Priorities for peer support delivery among adults living with chronic kidney disease: a patient-oriented consensus workshop

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ABSTRACT

Background: Peer support can address the informational and emotional needs of people living with chronic kidney disease (CKD) and enable self-management. We aimed to identify preferences and priorities for content, format, and processes of peer support delivery for patients with non-dialysis CKD and their loved ones.

Methods: Using a patient-oriented research approach, we conducted a half-day virtual consensus workshop with stakeholder participants from across Canada, including patients, caregivers, peer mentors, and clinicians. Using personas (fictional characters), participants discussed and voted on preferences for peer support delivery across format, content, and process categories. We analyzed transcripts from small- and large-group discussions inductively using content analysis.

Results: Twenty-one stakeholders, including 9 patients and 4 caregivers, participated in the workshop. In the voting exercise, participants prioritized peer mentor matching, programming for both patients and caregivers, and flexible scheduling (*format*); informational and emotional support focus (*content*); and leveraging kidney care programs and alternative sources (e.g., social media) for promotion and referral (*process*). Analysis of workshop transcripts complemented prioritization results and emphasized tailoring of peer support delivery to accommodate the diversity of people living with CKD and their support needs. This concept was elaborated in 3 themes: 1) Alignment of program features with needs, 2) Inclusive peer support options, 3) Multiple access points.

Interpretation: We identified preferences for peer support delivery for people living with CKD and underscore the importance of tailored, flexible programming in this context. Findings could be used to develop, adapt, and/or study CKD-focused peer support interventions.

PLAIN LANGUAGE SUMMARY

Approximately 10% of Canadians live with chronic kidney disease. Peer support is a way of connecting people with shared experiences and providing information and emotional support to patients along their kidney disease journey. We held a workshop with participants from across Canada to determine the preferences and priorities for providing peer support to people with chronic kidney disease. Our research team included 2 patient partners, who contributed to all phases of the research. The half-day workshop took place virtually and included patients with chronic kidney disease, caregivers, peer mentors, and healthcare providers. Participants referred to personas (fictional characters) when discussing content, format, and processes of peer support delivery in small- and large-group sessions. They then voted on their preferred options from each category. Participants prioritized ‘matching’ patients with peer mentors based on similar characteristics, flexible scheduling, and distinct program options for caregivers. They also wanted to increase awareness of peer support through specialty kidney care clinics and other sources, such as social media. In our analysis of transcripts from workshop discussions, participants emphasized a need to adapt, or tailor, how peer support is delivered to people with chronic kidney disease depending on their questions, needs, or concerns at that given moment. Participants encouraged kidney care teams to repeatedly introduce peer support to patients and their loved ones and to ensure access to any interested person. These findings will help guide how peer support programs are designed and offered to people with chronic kidney disease.

INTRODUCTION

People living with complex chronic conditions are tasked with self-managing their health and navigating the health system alongside day-to-day demands.[1,2] For the 10% of Canadian adults with chronic kidney disease (CKD),[3] unique challenges include balancing dietary recommendations, medication burden, and lifestyle strategies to slow progression of their disease with other competing priorities.[2,4-6] While multi-disciplinary CKD care models are well suited to supporting patients' medical and informational needs, particularly among those at high risk of kidney failure,[7-9] support gaps persist due to factors such as time-constrained clinic visits, the dynamic trajectory of CKD, and the care team's lack of lived experience of the condition.[10,11]

Peer support offers a complementary approach to supporting individuals' emotional needs, validating their concerns, and sharing knowledge through non-medicalized interactions with others with similar health-related experiences.[12] Given the national interest in patient-targeted strategies to enhance CKD self-management, opportunities to integrate peer support into comprehensive kidney care models are being increasingly sought.[13] Among people with non-dialysis CKD, who may be asymptomatic or lack overt disease manifestations, formalized peer support can establish a sense of community and equip them with knowledge and confidence to face an often-uncertain future.[14-16] Despite a perceived need by patients, their loved ones, and kidney care providers, evidence suggests variable awareness and uptake of peer support programming.[14,17-19]

Little is known about the extent to which formalized peer support structures meet the needs for people living with advanced, non-dialysis CKD, whose disease experiences can differ substantially from individuals with kidney failure and/or who receive kidney replacement therapy (i.e., dialysis, transplantation). In the context of our broader, patient-oriented research program, the aim of this consensus workshop was to identify preferences and priorities for content, format, and processes of peer support delivery for patients with CKD and their loved ones in Canada.

METHODS

Study design

We held a half-day virtual workshop using the Zoom™ online platform to engage stakeholders in a modified nominal group technique (NGT).[20,21] Our protocol is outlined in Figure 1 and Appendix 1. During the workshop we referred to six unique personas (i.e., fictitious descriptions of potential users)[22] developed previously in partnership with patients to prompt discussion about needs and preferences related to the content, format, and processes of formalized peer support delivery (Appendix 2).[4,23] We have reported this work in accordance with the Guidance for Reporting Involvement of Patients and Public (GRIPP2)[24] and the Consolidated Criteria for Reporting Qualitative Research.[25]

Participants and setting

The workshop took place in the summer of 2021. Eligible participants included adults living with non-dialysis CKD (regardless of etiology or duration), informal caregivers (e.g., family members, friends), clinicians, and other relevant stakeholders with an understanding of CKD and interest in peer support. Peer mentor volunteers from the Kidney Foundation of Canada were also eligible. We recruited participants comfortable communicating in English from across Canada by email invitation using established partnerships with the Canadians Seeking Solutions and Innovations to Overcome Kidney Disease (Can-SOLVE CKD) patient-oriented research network and the Kidney Foundation of Canada. We identified additional patient/caregiver participants from prior qualitative work who had consented to contact about future research. We sampled purposively across stakeholder roles to ensure diversity in perspectives and aimed for 20-25 participants, which is acceptable for a virtual, consensus-based exercise.[4,13]

Two weeks before the workshop we distributed materials by email. Participants were asked to review the personas, consider how they might access peer support, and reflect on how their own experiences may have shaped their views. Research team members were available by email or telephone for assistance. All participants completed a questionnaire to summarize their demographic characteristics.

Data collection

At the start of the workshop, the main facilitator (M.J.E.) welcomed participants and provided a program overview. Over a series of small-group sessions (comprised of 6-8 individuals across stakeholder groups), participants discussed potential content, format, and processes of peer support delivery in relation to the personas. Experienced facilitators referred to a topic guide (Appendix 3) and prompted participants to assume the perspectives of the personas during discussions. Following each small-group session, facilitators presented a summary of their group's ideas to the larger group and solicited feedback. Prior to the final prioritization exercise, the research team met to consolidate and categorize preferences discussed during the workshop. We used cumulative dot voting (i.e., 'dot democracy'), whereby participants used the annotation feature of Zoom™ to vote on 3 individual ideas/suggestions under each of the 3 categories (content, format, process) that they considered most important for people living with advanced CKD (i.e., up to 9 votes per participant). All sessions were audio-recorded and transcribed.

Patient engagement

Two patient partners (N.V., D.S.) with lived experience of kidney disease collaborated on the design, conduct, interpretation, and reporting of this project. Both contribute to our group's self-management and peer support-related research initiatives within the Can-SOLVE CKD Network. One patient (N.V.) with qualitative research experience facilitated small-group sessions, and one (D.S.) participated in data collection (i.e., workshop participant). Patient partners reviewed final outputs and contributed to manuscript preparation. Approximately one month after the workshop, all participants (including patients) had the opportunity to provide feedback and request clarification on a summary of findings circulated by email.

Data analysis

We summarized demographic and workshop data descriptively. To rank preferences within each category, we tallied the number of votes and ranked results as high ($\geq$7 votes), medium (3-6 votes), and low (<3 votes) priority. Two research team members reviewed field notes and transcripts to verify that all key features raised during discussions were captured in the voting exercise. Responses from a satisfaction survey distributed following the workshop were summarized descriptively (Appendix 4).

Transcripts from small- and large-group sessions were uploaded to NVivo 12 (QSR Pty International) to facilitate data organization. Three research team members (M.J.E., S.L., B.B.) inductively analyzed transcripts using conventional content analysis to identify themes related to peer support delivery prioritized by stakeholders.[26-28] Each team member independently reviewed transcripts, highlighted meaningful segments of text, and developed initial codes using the first small- and large-group discussion. We discussed, refined, and applied final codes to the remaining transcripts, from which we derived themes with representative quotes.

Ethics approval

This study was approved by the University of Calgary Conjoint Health Research Ethics Board (REB21-0423). All participants provided written informed consent.

RESULTS

The workshop included 21 participants: 5 patients, 4 caregivers, 4 peer mentors, 6 clinicians, and 2 organizational representatives. Three-quarters of participants were from Alberta. Most participants identified as female (76%), were between 40 and 64 years of age (62%), and had a university or professional degree (71%). Patient participants reported a range of CKD causes and disease durations (Table 1). All peer mentors reported having experience of both dialysis and transplantation.

Prioritization results

Within the format area, the most highly prioritized options ($\geq$7 votes) included peer mentor matching based on characteristics and support need, offering peer support to both patients and caregivers, and ensuring flexible programming to suit the wide variation in individuals' needs (Table 2). Conventional formats, such as group/one-on-one and telephone sessions, were more highly prioritized than virtual, social media, or informal activities. With respect to content, participants prioritized informational and emotional support over reassurance and validation (i.e., appraisal support) and assistance with day-to-day tasks. Within the process category, using social media to raise awareness about peer support and facilitating referrals through kidney clinic staff were highly prioritized.

Thematic findings

Participants identified the need to individualize, or tailor, peer support delivery for people with CKD as an overarching concept across sessions and stakeholder roles. Participants suggested the diversity of people with CKD should be reflected through a variety of flexible options across the format, content, and process categories. We characterized 3 themes and provide a thematic summary, supporting quotes, and suggestions to enhance peer support delivery in Figure 2.

Alignment of program features with needs

Participants suggested that the 'what' and 'how' of peer support delivery should match an individual's needs at that moment in time. Perceived support need and receptivity depended on factors such as disease duration, rate of progression, and understanding of their prognosis. For example, whereas patients with a recent diagnosis might benefit from emotional and informational support to promote disease acceptance and understanding, those with progressive disease may turn to peers for assistance with treatment decision-making. Stakeholders emphasized matching peer support users with mentors on defined demographic characteristics when facing relatable life challenges, such as matching the young woman persona with questions about family planning with another young woman with CKD. Matching based on mentor experiences (e.g., dialysis, transplantation) was considered important when people sought information about what to expect from kidney failure and its therapies. Participants suggested a one-on-one delivery format was better suited to interpersonal connection, whereas structured group sessions with peer facilitation could enable exchange of credible, disease-related information.

Inclusive peer support options

Participants highlighted peer support accessibility challenges related to the geographic and ethnocultural diversity of people living with CKD in Canada. Several clinicians noted inconsistent access to technology and limited options to connect with peers in rural/remote and Indigenous communities. Stakeholders emphasized a need for peer support programming appropriate to the needs of ethnocultural minority populations. They encouraged peer matching with mentors fluent in patients' primary language, engagement of community or faith-based organizations, and support resources that respect cultural traditions. A gap in distinct programming for caregivers was noted, whereby access to peer support independently from their affected loved one and from trained caregiver mentors could help normalize their experiences and provide strategies for managing in this role.

Multiple access points

Participants acknowledged individuals' varying levels of disease acceptance and readiness to engage in peer support throughout their illness journey. They prioritized peer support as a complementary strategy to multi-disciplinary CKD care at multiple time points and from multiple sources. Although patients may not be ready to access peer support early in their disease course, participants suggested introducing it at diagnosis or upon intake into a multi-disciplinary CKD program, re-visiting it regularly thereafter, and being poised to refer patients once they express interest. They also encouraged peer support promotion by multiple sources, such as care teams and community organizations, and using traditional (e.g., brochures) and non-traditional (e.g., social media) approaches.

INTERPRETATION

In our patient-oriented consensus workshop, stakeholders collaboratively identified priorities for peer support delivery in the non-dialysis CKD context. Top priorities across format, content, and process categories included mentor-mentee matching, distinct caregiver programming, and engagement of kidney care teams in introducing and referring to peer support programs. Our thematic findings complement the prioritization results and highlight a need for tailored, flexible peer support to mirror the dynamic nature of CKD and patients' varied experiences. Participants acknowledged potential accessibility challenges and identified repeated program endorsement as a key driver to enhance uptake.

In Canada, the Kidney Foundation has been the main source of kidney-focused peer support that connects any interested individual affected by kidney disease with trained peer mentors using telephone, in-person, and virtual formats.[29] However, few multi-disciplinary CKD clinics embed peer support within their care programs.[19] Individuals with advanced, non-dialysis CKD often lack overt manifestations yet face challenges related to high symptom burden, metabolic complications, and difficult treatment-related decisions (e.g., choosing among dialysis types).[30] Thus, our findings endorse an inclusive but tailored approach to peer support that purposefully addresses CKD-specific support gaps and connects individuals within the broader kidney community. This includes distinct peer support programming for caregivers, who experience high physical, mental, and financial burden yet whose needs are often overlooked.[31,32] Findings from a recent randomized controlled trial showing reduced CKD-related caregiver burden with online peer mentoring support further dedicated study in this area.[33]

Workshop participants prioritized peer mentor matching based on shared characteristics or circumstances, which can promote bonds and positive social comparisons among people with chronic conditions.[12] Whereas some patients with CKD prefer mentors with more advanced disease (e.g., dialysis, transplantation) to help them navigate their disease trajectory,[14] others prefer matching on factors such as gender, age, or ethnicity, depending on context.[34] Mentor-mentee matching by similarity may not always enhance intervention effectiveness, and some have raised questions about its value and impact on the peer support relationship.[16,35] Perhaps more important than matching or 'brokering' the relationship is creating opportunities for patients to build rapport with potential mentors and find the right fit based on current needs.[36]

The challenges to peer support access raised by workshop participants highlight an important gap in program delivery. Nearly one fifth of the Canadian population resides in rural or remote areas, among whom recognized disparities in access to kidney-related care exist.[37-39] Findings from a scoping review suggest that peer support programs in other chronic conditions are tailored to address both unique issues faced by people living rurally and barriers to access.[40] Research on existing support structures, preferences for peer support, and barriers to program use for rural-/remote-dwelling individuals with CKD is needed. Other accessibility issues raised during our workshop (e.g., perceived lack of ethnoculturally appropriate peer support resources) draw attention to the need for community engagement to ensure program inclusivity and culturally safe practices. Approaches to integrating peer support across regional/national providers (e.g., CKD programs, external organizations) and evaluating its effectiveness are additional knowledge gaps requiring further study.

Limitations

Most participants other than peer mentors had limited experience with peer support yet were engaged in the topic and contributed to the discussion. Although social desirability may have influenced the discussion and final priorities, voting was anonymous. As we were unable to determine stakeholder role from audio-recordings or 'dot' votes, we could not attribute priorities to specific participant groups and thus present integrated findings. The virtual format may have limited interpersonal connection and interaction, and although participants were satisfied with the format, they suggested additional time to discuss this nuanced topic would have been helpful. Lastly, participants were English speaking, mostly Caucasian, and had internet access, technological proficiency, and high educational attainment. Although accessibility issues were raised, it is possible that participants with different characteristics may have identified additional considerations.

Lessons learned from patient engagement

We used a patient-oriented research approach to address a priority area for patients with CKD and learned from the lived experience of our patient partners through their contributions to study design and conduct. Small-group facilitation by a patient partner encouraged reflective discussions, and patient engagement in those discussions brought insight into the practicalities of living with CKD. In synthesizing and reporting our findings, patient partners provided suggestions to ensure key messages resonate with a non-academic readership. Importantly, our patient partners are deeply invested in this topic and improving the lives of people with kidney disease, on which we commit to furthering our collaboration through future work.

Conclusion

We identified through a consensus workshop approach the priorities of patients and other stakeholders related to peer support delivery for people with non-dialysis CKD. Flexibility, tailoring, and inclusivity would be important program features to consider when developing and/or implementing peer support interventions in this context. Findings will inform future work to enhance supports for people with CKD through continued engagement with patient partners.

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DISCLOSURES

None.

AUTHORS' CONTRIBUTIONS

Meghan Elliott, Maoliosa Donald, Nancy Verdin, Danielle Fox, and Brenda Hemmelgarn contributed to the conception, design, and methodological approach of this study. Meghan Elliott, Maoliosa Donald, Janine Farragher, Nancy Verdin, Shannan Love, and Kate Manns participated in facilitation and/or note taking during the workshop. Meghan Elliott, Shannan Love, and Brigitte Baragar undertook data analysis and summarized findings. Nancy Verdin and Dwight Sparkes provided important insight into study findings from their perspectives as patient partners. All authors provided critical review of the manuscript, gave final approval of the version to be published, and agreed to be accountable for all aspects of this work.

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FIGURE LEGENDS

Figure 1. Overview of consensus workshop approach

Figure 2. Thematic summary, supporting quotes, and suggestions to address priorities for peer support delivery

SUPPLEMENTARY MATERIAL

Appendix 1. Consensus workshop protocol

Appendix 2. Example of a patient persona

Appendix 3. Topic guide for peer support consensus workshop

Appendix 4. Peer support consensus workshop evaluation

TABLES

Table 1. Participant characteristics

Characteristic	All (n=21)
Geographical location	
Alberta	15
Ontario	4
Saskatchewan	1
Manitoba	1
Employment status	
Full-time	14
Retired	4
Part-time	1
Disability, Not employed	2
Education[a]	
University degree	11
Professional or graduate degree (e.g., MD)	4
Technical Diploma	3
High School	2
Age (years)	
Under 40	4
40-64	13
65 or older	4
Ethnicity	
Caucasian	18
Asian	2
Latina	1
Gender	
Woman	16
Man	5
	Patients (n=5) and Caregivers (n=4)[b]
Marital status	
Married	7
Common Law	2
Divorced	0
Single	0
Cause of CKD[c]	
Diabetes	4
High blood pressure	1

Glomerulonephritis	1
Other	1
Time with CKD (years)[c]	
Less than 5	2
5-9	2
10-20	3
Self-reported kidney function (eGFR in mL/min/1.73 m^2)[c]	
Below 15	2
15-29	0
30-44	0
45-60	1
Unsure	4
	Peer mentors (n=4)
Length of time as mentor (years)	
1-4	1
5-10	0
More than 10	3
Treatment experience[d]	
Kidney transplant	4
Hemodialysis	4
Peritoneal dialysis	2
	Non-patient stakeholders (n=8)
Role	
Allied health	2
Nephrologist	2
Nurse/Nurse practitioner	2
Peer support program representative	2
Time in current position (years)	
Less than 10	2
10-15	2
More than 15	6
Clinical time in current role (%)	
Less than 25	1
25-50	1
More than 50	4
Not applicable	2

[a] One participant did not respond.

[b] Caregivers attended either with (n=2) or without (n=2) their loved one with CKD.

[c] Only patients with CKD and caregivers without a loved one in attendance responded; n=7 for these questions.

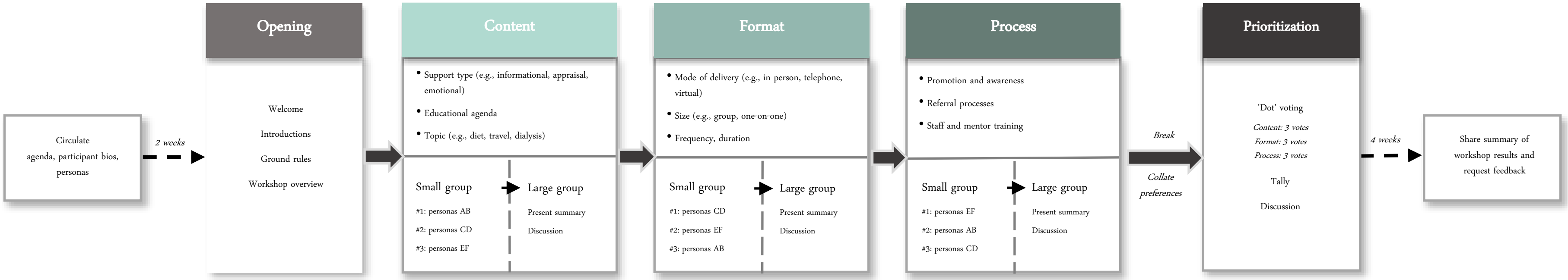
[d] All peer mentors reported having experience with peritoneal dialysis, hemodialysis, or both in addition to transplantation.

Abbreviations: CKD, chronic kidney disease; eGFR, estimated glomerular filtration rate; MD, medical doctor

Table 2. Peer support in CKD topic areas with suggested options, corresponding dot counts, and priority status

Category	Suggested Options	Dot count	Priority*
Peer support format			
Who delivers	Matching peer mentor	11	**High**
	Knowledgeable and trained peer mentor	6	**Medium**
	HCP involvement in peer support	3	
	Varied mentor experiences	1	**Low**
Who receives	Combination of persons with CKD and caregivers	8	**High**
	Person with CKD	3	**Medium**
	Family members, caregivers	2	**Low**
	Public	1	
How delivered	Small group	3	**Medium**
	One-on-one	3	
	By telephone	3	
	By email or direct messaging	3	
	In-person	1	**Low**
	Virtual	1	
	Blog or social media	1	
	Social activities	1	
When delivered	Flexible	8	**High**
	Scheduled	3	**Medium**
	On-going	1	**Low**
Peer support content			
Informational support	What to expect with kidney disease	9	**High**
	Hands-on experience	3	**Medium**
	Diet	3	
	Travel	2	**Low**
	Family planning, sexuality	1	
Emotional support	Feeling supported and not alone	7	**High**
	Coping and coaching skills	4	**Medium**
	Building relationships with peers and others	4	
Appraisal support	Reassurance and validation	4	**Medium**
Instrumental support	Day-to-day tasks	1	**Low**
Caregiver support	Dedicated caregiver programming	6	**Medium**
Peer support processes			
Promotion of peer support	Social media	8	**High**
	Organizational outreach	6	**Medium**
	Peer mentors on-site	5	
	Brochures, posters	1	**Low**
	Cultural organizations / avenues	1	
Referral to peer support	Clinic-initiated	14	**High**
	Repeated reminders	10	
	Self-referral	2	**Low**
	Mandatory peer support	2	

[*] Priority assignment based on number of votes (i.e., ‘dots’) as follows: high (≥7 dots), medium (3-6 dots), low (<3 dots)


Circulate
agenda, participant bios, personas
2 weeks
Opening
Welcome
Introductions
Ground rules
Workshop overview
Content
Support type (e.g., informational, appraisal, emotional)
Educational agenda
Topic (e.g., diet, travel, dialysis)
Small group
#1: personas AB
#2: personas CD
#3: personas EF
Large group
Present summary
Discussion
Format
Mode of delivery (e.g., in person, telephone, virtual)
Size (e.g., group, one-on-one)
Frequency, duration
Small group
#1: personas CD
#2: personas EF
#3: personas AB
Large group
Present summary
Discussion
Process
Promotion and awareness
Referral processes
Staff and mentor training
Small group
#1: personas EF
#2: personas AB
#3: personas CD
Large group
Present summary
Discussion
Break
Collate preferences
Prioritization
'Dot' voting
Content: 3 votes
Format: 3 votes
Process: 3 votes
Tally
Discussion
4 weeks
Share summary of workshop results and request feedback

Tailoring Peer Support to Address Individual Needs

Themes and concepts	Supporting quotes	Suggestions to address priority area
Theme 1: Alignment of program features with needs		
Responsive content	*"Talk about things that bother her. Maybe learn a bit more about the disease, whatever she needs. Or she also may on the other hand, everything sort of has two hands so you sort of have to get to know who you are talking to and where suits them best." (Small group 3)* *"She wants to have nutrition advice. Well that works out well with a group session. Whereas maybe she wants some help with depression or mental health and that might be more one-on-one. So it would depend on what she's wanting the peer support for." (Small group 3)*	• Readiness assessment • Patient-informed content • Peer-led educational sessions • Hands-on observation experiences • Expert co-facilitation
Tailored format	*"Like there are so many different avenues for patients to receive peer support and it depends on at the time they need it which scope suits their personal needs at that point." (Small group 3)* *"It sounds like she would need flexibly and scheduling something that was more formal would be more difficult for her. So being able to connect with somebody either over the phone or through Facetime or Zoom. If it needs to be face-to-face it's going to be more accessible for her than something that is scheduled that she has to attend." (Small group 1)*	• Convenient setting (e.g., home, clinic visits) • Flexible format options • Tailored to support type (e.g., one-on-one for emotional support) • Longitudinal peer relationships
Mentor-mentee matching	*"I think Cory [persona] being new to the role of caregiver, might appreciate speaking one-on-one with another man who is also being a care partner to his spouse. That might be a very comfortable way to enter conversation and gain some support from someone else who has lived the same experience." (Small group 2)* *"Your goal is to just find somebody with a few things in common because to realize as a patient that you are not alone is so powerful and you may not have every, you may not have the same kidney disease or you may not be the same age, but if you've got a similar experience it's very, very valuable." (Large group)*	• Matching by demographic characteristics • Matching by lived experiences • Recruiting and sustaining diverse peer mentor involvement
Theme 2: Inclusive peer support options		
Program accessibility	*"The reserves do not have internet, some of them in the northern reserves, so there is no virtual. Data is expensive, many people don't have data and especially with COVID there are very few people going into reserves." (Small group 2)* *"We have a multicultural city, so I find also it would be helpful I think if her dad could speak to somebody in his own language...sometimes you just need someone just to talk to and then being in your own language it makes it, you just feel more comfortable." (Small group 1)*	• Local peer support availability • Technical assistance • Engagement of community resources (e.g., Indigenous leaders) • Culturally and linguistically appropriate resources
Distinct caregiver programming	*"It would be important to reach out to his [patient's] wife as well because she is wanting the information and this is going to impact her life." (Small group 2)* *"I guess my question is like for Becca [caregiver] like what is she trying to get support with? Is it trying to get support in general as in peer support or is it more asking questions about the needs of her father. That's going to change, I guess the types of support she wants is based on her needs at the time." (Small group 1)*	• Assessment of caregiver needs • Options for joint (with patients) and separate peer support • Trained caregiver peer mentors • Caregiving-focused peer support programming
Theme 3: Multiple access points		
Multiple times	*"People are so overloaded sometimes with information or stress or whatever it might be and it's so much physically going out and looking [for peer support]. Of course they are going to [go] for it, it's something they could benefit from, but they don't quite know that they need it yet." (Small group 3)* *"Learning about something once is not sufficient. Often times people are at different stages of readiness in their journey and readiness to hear things, readiness to want or need to access things." (Large group)*	• Early peer support introduction • Re-introduction at regular intervals or based on need • Ongoing readiness assessment
Multiple referral sources	*"So it's educating the entire clinic about what's available so that when they hear this caregiver speak up they know, oh maybe it's a good idea to connect with the peer support program or other peer programs that are available." (Small group 3)* *"If I think about my Chinese parents or my Chinese grandma, they get a lot information from word of mouth. Their friends who are also from the same heritage as them also get information from the Chinese newsletters, Chinese website. You know these are a lot of platforms where they get their information from so I'm not sure if that would be appropriate for people to promote peer support." (Small group 3)*	• Programming through external organizations (e.g., Kidney Foundation of Canada) • Peer support embeddedness within kidney care programs • Integration with patient education • Informal peer support through social activities
Multiple support settings	*"How he [patient] can be supported and in terms of that support being defined both as more formalized professional support such as allied health around those information needs and emotional needs but also in the community around." (Large group)* *"In terms of that support being defined both as more formalized professional support such as allied health around those information needs and emotional needs but also in the community around, for example with Cory was his church group. (Large group)*	• Widespread availability of promotional material • Staff education about programs • Routine discussions about peer support with clinic personnel • Peer support referral by care team

Appendix 1. Protocol for peer support consensus workshop

Table of Contents

1.0 BACKGROUND AND STUDY RATIONALE

Chronic kidney disease (CKD) is a multifaceted condition that can pose challenges to self-management and contribute to lower health-related quality of life compared with the general population.[1] Patients with advanced non-dialysis CKD often face metabolic complications and symptoms that can become increasingly complex to manage alongside their other comorbidities and daily responsibilities.[1] As kidney disease progresses, this management burden is compounded by critical treatment-related decisions and transitions in care, primarily related to kidney replacement therapies, such as dialysis or transplantation.[2] Patients and their families can become overwhelmed with the complexities of not only living with non-dialysis CKD but the added responsibility of making these difficult decisions,[3, 4] which are heightened as they approach kidney failure. Although 1 in 10 adults worldwide live with CKD, the majority lack overt manifestations, and thus the "invisibility" of this condition can also contribute to feelings of isolation and loneliness in not appreciating others living similarly with the disease and its associated challenges.[5]

Peer support has been increasingly recognized as a way of providing support for those experiencing similar challenges related to their chronic disease. In sharing their lived experiences, the parties involved have the opportunity to both provide and receive social and emotional support, which can promote psychological wellbeing and coping.[3] For patients with kidney disease across CKD stages, meeting other patients and hearing their experiences can help to better understand the reality of living with different treatment options and assist in this decision making process.[6] People with non-dialysis CKD who have received peer support acknowledge that it can be a potentially useful adjunct to medical care in its ability to provide reassurance, normalize the experience of living with CKD, and instill optimism in a person's ability to successfully cope with the disease.[3]

Although peer support has been recognized as an important and complementary aspect to chronic disease care, many unknowns exist with respect to how such an approach could be integrated into the care of patients with kidney disease. Whereas some studies have examined the experiences with formal peer support of people across CKD stages (including non-dialysis, dialysis, and transplant), the perceived role of peer support in enhancing non-dialysis CKD care remains largely underappreciated.[7] As part of this program of research, a qualitative study was conducted to explore CKD patients' care experiences, support environment, understanding of peer mentorship, and how others with kidney disease address identified support gaps in a local context. Results showed that although patients and caregivers had limited experience with peer support, participants across all roles acknowledged the value in support for persons living with advanced non-dialysis CKD by peers who appreciate the CKD lived experience and thus can help them prepare and adapt as their condition progresses. In this way, patients anticipated gaining confidence in living with and managing their kidney health. A national survey of multidisciplinary CKD clinics was then completed to identify healthcare providers' perceptions of peer support in CKD care, including their awareness of peer support programs and potential opportunities to incorporate peer support into existing CKD care. Preliminary results from this study show that healthcare providers have varied degrees of awareness and access to peer support as part of their CKD clinic, yet value the potential role that peer support can play in enhancing care for patients with CKD and their caregivers.

The next step in this research will be to explore the preferences of patients with CKD, their caregivers, and healthcare providers regarding characteristics of a peer support intervention.

These preferences will then be prioritized using a modified nominal group technique. These results combined with previous findings will provide a more complete picture of the perceived value of peer support in addressing CKD patients' support needs and how peer support can help promote CKD management. We will ultimately use identified priorities and preferences for peer support to inform the implementation of peer support into existing CKD care.

2.0 RESEARCH OBJECTIVES

1. To further explore the experiences and preferences of adults with non-dialysis CKD, their caregivers, and healthcare providers regarding peer support interventions.
2. To prioritize preferences for peer support, including characteristics of peer support that are considered important for adults with non-dialysis CKD and their caregivers.

3.0 METHODS

A consensus workshop will be used to address Objectives 1 and 2. A half-day virtual workshop using a modified Nominal Group Technique (NGT) with patients, caregivers, healthcare providers, peer mentors from the Kidney Foundation of Canada's 'Kidney Connect' program, and other relevant stakeholders will be held. Workshop participants will review and rank peer support characteristics that were previously identified in prior and ongoing studies as part of this program of research (i.e., qualitative study, environmental scan, scoping review). The NGT has been commonly used as a consensus technique that is appropriate for lay people to complete and can be easily adaptable.[8] Although the NGT usually utilizes face-to-face interaction, it will be adapted to a virtual format given the current COVID-19 pandemic. Our modified NGT process will result in a set of prioritized recommendations for a peer support intervention targeting people with non-dialysis CKD and their caregivers. Recommended characteristics of the intervention may include features (e.g., target audience, mode of delivery, format, level of facilitation, characteristics of facilitator); content areas (e.g., curriculum, educational components, mental health and wellbeing); and processes (e.g., patient identification, referral, educating staff). We plan to use personas of potential peer support users (i.e., patients with CKD and their caregivers) to guide and raise awareness of user needs in this co-development stage (i.e., consensus workshop) of a peer support intervention.

3.1 Participant selection and recruitment

We will use purposive sampling to identify patients and caregivers, healthcare providers, and peer mentors who have previously participated in peer support research projects completed by this research team and have consented to be contacted about future research. These potential participants will be sent a letter of invitation to participate and will be asked to contact a research team member by email or telephone as indicated in the letter of invitation if they are interested in learning more about the workshop or are interested in participating.

Through our team's established partnerships with the Can-SOLVE CKD Network and Kidney Foundation of Canada (KFOC), we will identify and approach additional potential participants. Potential participants will be sent the letter of invitation and asked to either contact a research team member directly or to sign a Consent to Contact form allowing the research team member to contact them. Snowball sampling will also be used to further identify participants with an interest in peer support using a similar recruitment process.

Eligible participants will be English speaking adults 18 years or older who are patients with a diagnosis of non-dialysis CKD or kidney failure (i.e., experience with kidney replacement therapies), family members or informal caregivers of patients with CKD, peer mentors from KFOC's 'Kidney Connect' program. We will also invite healthcare providers and other stakeholders who have a strong understanding of CKD and interest in peer support. We will aim to recruit 20-25 individuals to participate in the consensus workshop. Past research by our group using similar modified NGT methodology recommends 20-30 people for participation in a priority setting exercise, with representation of patients, caregivers, clinicians, and decision makers.[9] Two weeks before the workshop, participants will be provided with a summary of results from previous and ongoing peer support research completed by this group. They will also be asked to reflect on their personal experiences with chronic kidney disease, what questions they might have for someone with lived experience of kidney disease, and possible ways of accessing this type of support. Prior to the workshop, participants will be informed about the purpose of the workshop as a research project, their role, risks/benefits, confidentiality and privacy of records. They will be asked to provide informed consent prior to the start of the workshop.

3.2 Data Collection

Baseline data will be collected by a research team member upon enrollment for the workshop and will include demographic information; stakeholder role; clinical characteristics (patient); duration and frequency of support provided (caregivers); location, duration and type of practice (healthcare providers); and organization (mentors, other stakeholders). An agenda for the workshop will be developed and will include a description of the day's activities including ground rules (i.e., open conversation, listening, consideration for other participants' views in an open and respectful manner). A trained research team member will observe participants during the group discussions to document both verbal and non-verbal interactions between group members. Group discussions will be audio recorded by facilitators using individual handheld digital audio-recorders to help clarify any discrepancies that may arise from the discussions.

The consensus workshop will be held virtually using the Zoom online platform. During the workshop, three to four small breakout groups (6-8 people each, composed of various stakeholder participants) will provide their views on peer support characteristics. We will use previously developed personas to represent hypothetical patients with CKD and caregivers to help structure and facilitate conversation among participants.[10] We will ask participants to assume a persona lens and provide input regarding the persona's peer support needs. Facilitators (i.e., research team members) with experience in NGT will lead the groups, encouraging participants to express their views and opinions while also listening to different perspectives. The workshop will be divided into three stages:

1. First, small group discussions will involve participants providing input regarding a persona's peer support needs and preferences. These group discussions will be facilitated by a trained team member. Discussions will be captured by a note taker and audio recorded. Each group will focus on a different peer support characteristic (i.e., features, content areas, or processes), then will prioritize their top preferences to bring to the larger group for further discussion and refinement.
2. Second, a large group discussion will follow to share preferences from each small group. A representative from each group will share a summary of their group's ideas and preferences. A list of preferences for peer support features, content areas, and processes will be generated. A cumulative voting technique approach using either the annotation or polling features on Zoom will be used to allow participants to indicate their top preferences. They will be asked to indicate their top three preferences for each peer support area (i.e., features, content, and processes) either by placing an annotation beside their preferences on the screen or indicating their preferences in a polling question.

3. The preferences will then be ranked by tallying the preferences and ranking each peer support feature, content area, and process as high, medium, or low priority based on the number of annotations/polling responses assigned to each.

3.3 Data Analysis

The analysis will be based on methods used in previous modified NGT studies used to identify outcomes in kidney transplantation and preferences for a CKD self-management e-health tool.[10, 11] We will use descriptive analysis for demographic and workshop data. Preferences will be ranked for peer support characteristics using the cumulative voting technique approach. Annotations or polling responses for each peer support characteristic will be tallied and ranked as high ($\geq$7), medium (3-6), or low (<3) priority. Two team members will independently review the list of preferences, all field notes, and audio and written data from the workshop to ensure all information was captured. A narrative of the field notes obtained from observation of group discussions will be presented to enrich the content of the findings.

Three research team members will undertake conventional content analysis of transcripts from small- and large-group sessions to complement the prioritization results.[12] They will develop initial codes inductively based on meaningful segments of text from the first small and large groups, which they will discuss, refine, and apply to subsequent transcripts. Additional codes capturing new concepts will be added to the coding scheme as it evolves. After coding all transcripts, codes will be reviewed in relation to one another and the original transcript data, and themes will be developed to capture patterns from the data in relation to the workshop objectives. We will present final themes with their descriptors and representative quotes. In qualitative research, sampling, data collection, and analysis typically proceed until data saturation is attained (i.e., the point at which no new relevant data is attainable).[13] However, given the fixed sample size of the workshop, content analysis will be possible only on available small- and large-group transcripts.

Upon completion of the workshop, participants will be sent a post-workshop questionnaire assessing their satisfaction with the workshop and allowing them to provide comments and suggestions for improvement. Within one month of the workshop, a document will be shared with all workshop participants summarizing key findings. Participants will be asked to provide feedback if interested, which will be used to refine our presentation of results and identified themes.

4.0 ETHICAL CONSIDERATIONS

Ethical approval for this study will be obtained from the University of Calgary Conjoint Health Research Ethics Board (CHREB) prior to recruitment (REB21-0423). Informed consent will be obtained by a research team member prior to the consensus workshop. While there are no specific risks associated with participating in this research project, some participants might experience discomfort with the process or certain questions. As part of the informed consenting process, participants will be informed that they are able to decline answering questions during the workshops and are free to stop their participation at any point.

Because of the time commitment required to participate in the consensus workshop, participants will be provided with $75 reimbursement for their time and any expenses incurred. Participants will be asked to sign the required reimbursement form prior to the workshop.

Informed consent: Once participants have been identified and have expressed interest in the study, they will be given the opportunity to ask questions and request additional information about the study prior to providing consent by contacting a member of the research team. Participants will then be emailed or mailed an informed consent form to review prior to the workshop. They will have the opportunity to ask additional questions prior to providing consent. They will then be asked to either return the signed consent form by mail, email, or fax. If this is not possible, participants will be given the opportunity of providing informed oral consent.

Anonymity, Confidentiality, and Data Security: The privacy and confidentiality of all participant information will be reviewed with participants prior to the workshop. The consensus workshop approach is unique in that confidentiality cannot be guaranteed due to the nature of group participation and discussion. We will attempt to maintain confidentiality of all participants as much as possible by establishing ground rules that will be reviewed at the beginning and end of the consensus workshop. We will emphasize the confidentiality of information shared with the group and that this information should not be discussed outside of the group setting.

The virtual format of this consensus workshop offers additional risks to patient privacy and confidentiality. We will attempt to minimize these risks by using the Zoom online platform accessed using a password-protected University of Calgary to help protect participant confidentiality. Zoom has high level security precautions built in to help protect confidentiality. We will use recommended Zoom settings including the waiting room function and password protection to optimize privacy. Participants will be notified before the workshop that discussions will be audio-recorded using individual, handheld digital audio-recorders. We will also capture workshop content through screen shots of additional information collected on the Zoom platform and diligent note taking during group discussions. Recordings and documents will be uploaded to a password-protected computer on a secure University of Calgary server. These precautions will assist in maintaining confidentiality of the data collected and will be discussed with participants prior to the workshop. Following de-identification of the data, participants will only be referred to by their unique identification number. All analysis will be completed on de-identified data. Only workshop excerpts and direct quotes that do not reveal the participant's identity will be used in the final report.

Data transmission, storage, and archival: All data transmission (e.g., audio files) will occur using password-protected and encrypted files. Data storage and archiving will be in accordance with TCPS2, University of Calgary guidelines (i.e., 5 years from date project is closed or in accordance with the terms and conditions of the research agreement or funding agency), and Department of Nephrology SOP – Clinical Data Management procedures. All data will be stored at the University of Calgary. Hard copies of consent forms, demographic questionnaires, and other study related documents will be stored in a locked filing cabinet in a locked office. Electronic data will be kept in a password-protected file on a secure patient level data server at the University of Calgary (i.e., Citrix Research Data Haven within the IT department).

Dissemination: Findings will be reported through a report or presentation to inform relevant stakeholder groups and end-users of the knowledge gained from this project. Academic, clinical, and public forums and publications will be considered.

5.0 STRENGTHS AND LIMITATIONS

Findings from this study will be based on perspectives of patients, caregivers, peer mentors, healthcare providers and other relevant stakeholders from across Canada and will therefore relate to non-dialysis CKD care nationally. We will recruit participants with a range of demographic and clinical characteristics to provide a range of perspectives, preferences, and opinions. We will use a structured process for reaching consensus to ensure that peer support characteristics are as representative and generalizable as possible to patients with CKD across Canada. Despite this, the expressed views may not reflect those of participants who did not participate and findings will only be applicable to English-speaking adults.

6.0 SIGNIFICANCE

Patients and other stakeholders from across Canada have previously identified the need for optimal strategies to enable CKD self-management and prevent progression to kidney failure as a research priority.[14] Peer support was also identified as a strategic goal of Alberta Kidney Care South (AKC-S) Kidney Care Clinics. This program of research aligns with both of these priorities. Findings from this research will contribute to a better understanding of the preferences and priorities regarding peer support from the patient, caregiver, and healthcare provider perspectives nationally so that patient-centered peer support interventions can be developed.

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Appendix 2. Example of a patient persona

> *“It affected my family, I had to have my mom and dad come from China to help take care of my kids, I was too sick and my husband was working.”*

PERSONAL OVERVIEW:

Grace is a 36 years old living with her husband and two children in Vancouver. She works for a large accounting firm. Was diagnosed with chronic kidney disease 5 years ago and is unclear of the cause. She has had to take a lot of time off of work due to fatigue and feeling sick. She sees a traditional Chinese medicine physician to help her with her symptoms. She was active prior to her diagnosis, participating in activities with her children and running. She is driven and likes to have control over all aspects of her life. She feels that she is a burden on her family.

GOALS:

- To get back to running and participating in activities with her family.
- To reduce her absences from work.

WHAT’S WORKING:

- Integration of traditional/alternative medicine with Western medicine.

CHALLENGES:

She has had no guidance or support for managing her home and work life. She feels she is losing her role as an accountant, parent and wife. Her disease is taking a toll on her physical and mental health. She is unsure of what online sources are credible. She finds resources hard to follow, as English is her second language. Due to her busy life, she likes to buy food that is convenient to prepare, yet healthy.

Go-Getter Grace

Appendix 3. Topic guide for peer support consensus workshop

Agenda:

1. **Initial large group discussion** to provide background, participant introductions, workshop plan.
   - Review ground rules and Zoom etiquette.
   - Review that participants can add comments or questions in the chat box if they don't feel comfortable sharing in the group discussion. Note takers will also save all chat boxes to be reviewed later.
2. **3 separate, small breakout sessions**, each of which will focus on a different domain of peer support delivery.
   - Two personas will be used during each breakout session to help guide the conversation. Participants will be asked to assume a persona lens and provide input regarding the persona's peer support needs and preferences.
   - Facilitators will direct the conversation to focus on the specific domain and to use the personas to help frame the discussion.
   - Facilitators will probe: (1) why or why not participants chose certain peer support features for the persona; (2) what are the barriers and facilitators for the peer support feature; (3) what would make peer support successful for the persona.
   - At the end of the breakout session, participants will be asked to review the written notes to clarify or expand on any points.

3. **Large group discussion** after each breakout session.
   - Facilitators will summarize key findings from the breakout session discussion.
4. **Consensus voting activity**
   - Participants will be asked to choose their top 3 preferences for each domain of peer support using the persona lens and to vote using the Zoom annotation feature.
   - The activity will be followed by group discussion to discuss voting results including why participants voted for certain peer support features, reasons for their choices, barriers and facilitators to different choices, etc.

Breakout session #1 – Domain: **Format of peer support delivery**

Group #:
Facilitator:
Note taker:

Introduction	In this group, we will be talking about ideas for the format of peer support delivery. We want to explore the different ways this persona would prefer peer support be delivered. Let's spend a few minutes reviewing the first persona we will be using for this discussion. **Persona 1: Studious Sarah** - Sarah is a 20-year-old busy university student. She was born with poorly functioning kidneys and has numerous healthcare providers involved in her care. Despite having friends and family, she feels sad at times and would like to develop friendships with others her age who have CKD. She would also like information and support to help smoothly transition from being a minor to an adult in the healthcare system.	
Questions/Discussion **(5-10 minutes per persona)**	1. What peer support **format** would ________ (persona) prefer? Why? (e.g., 1:1, group, online, open house) Tell me more about this format. (e.g., frequency, duration, follow up) 2. How do you think _____ (persona) could best **access** (i.e., mode of delivery) this peer support opportunity? Why? (e.g., in person, by phone, virtual, online) 3. Tell me about what **who** ___________ (persona) would benefit from talking to. (e.g., other patients / caregivers, trained peer mentors)	**Notes:**

	Now let's review the second persona we will be using. **Persona 2: Travelling Travis** - Travis is a married, retired 69-year-old living in Toronto who enjoys spending winters in Florida. Despite being recently diagnosed with CKD, he does not think it is serious as he feels fine. His wife is concerned that he is in denial and might need dialysis. Travis and his wife have not been provided with information about CKD and how it could impact their ability to travel. Travis avoids technology and prefers talking about medical issues with his physician.	
	1. What peer support **format** would ________ (persona) prefer? Why? (e.g., 1:1, group, online, open house) Tell me more about this format. (e.g., frequency, duration, follow up) 2. How do you think _____ (persona) could best **access** (i.e., mode of delivery) this peer support opportunity? Why? (e.g., in person, by phone, virtual, online, synchronous vs asynchronous) 3. Tell me about what **who** ___________ (persona) would benefit from talking to. (e.g., other patients / caregivers, trained peer mentors)	**Notes:**

Breakout session #2 – Domain: **Content of peer support**

Group #:
Facilitator:
Note taker:

Introduction	In this group, we will be talking about ideas for the content of a peer support program. We want to talk about what this persona would want to get out of peer support. Let's spend a few minutes reviewing the first patient persona we will be using for this discussion. **Persona 1: Motivated Mark** – Mark is a 56-year-old divorced man living on a reserve. He has had CKD for 10 years but finds it difficult attending CKD clinic due to the distance. He would like to learn ways to feel better to work part time including information on affordable foods he can eat. Previous diet information from the clinic was too general and access to information on the internet is difficult due to unreliable internet.	
Questions/Discussion **(5-10 minutes per persona)**	**Persona 1:** 1. In what ways could peers help to **support** ___________ (persona)? (e.g., information, emotional support, help with day-to-day activities) Why do you think (persona) needs this type of support? 2. What **topics** would ___________(persona) benefit from talking to a peer about? Why? (e.g., travel, diet, coping skills, dialysis options, transplant process) How could this information be best shared with (persona)? (e.g., handbook, websites, in-person opportunities) 3. What other peer opportunities would be important to _______ (persona)? (e.g., informal social opportunities - coffee	**Notes:**

	meetings, social outings; specific programs for skill development -Heart Math).	
	Now let's review the second persona we will be using. **Persona 2: Busy Becca** – Becca is a 48-year-old mother of two who works full time. She looks after her father who has kidney disease and feels overwhelmed trying to manage the demands of her own family life with her dad's needs. She's looking for support to help her gain some "me time".	
	Persona 2: 1. In what ways could peers help to **support** ___________ (persona)? (e.g., information, emotional support, help with day-to-day activities) Why do you think (persona) needs this type of support? 2. What **topics** would ___________(persona) benefit from talking to a peer about? Why? (e.g., travel, diet, coping skills, dialysis options, transplant process) How could this information be best shared with (persona)? (e.g., handbook, websites, in-person opportunities) 3. What other peer opportunities would be important to _______ (persona)? (e.g., informal social opportunities - coffee meetings, social outings; specific programs for skill development -Heart Math).	**Notes:**

Breakout session #3 – Domain: **Processes of Peer support Delivery**

Group #:
Facilitator:
Note taker:

Introduction	In this group, we will be talking about ideas for processes related to a peer support program. We want to explore ways that this persona could access peer support. Let's spend a few minutes reviewing the first patient persona we will be using for this discussion. **Persona 1: Go-getter Grace** – Grace is a 36-year-old married mother of two. She was diagnosed with CKD 5 years ago and has had to take a lot of time off work as an accountant. She feels that her illness has taken a toll on her physical and mental health and has had no support in managing her home and work life. She is unsure what online sources are credible and finds resources challenging as English is her second language.	
Questions/Discussion **(5-10 minutes per persona)**	**Persona 1:** 1. (a) What would be the best method for _________ (persona) to **find out** about peer support? (e.g. directly from CKD staff, brochures, during education sessions) (b) When would be a **good time** for __________ (persona) to be introduced to peer support? Why? (e.g. start of CKD clinic, when pts need additional support) 2. How could __________ (persona) most easily **access** peer support? (e.g., referral process, ps integrated into CKD clinic, ps integrated into another self-management tool) 3. What would make a peer support program **successful** for (persona)? (e.g., having on-going access to a source of experiential knowledge; feeling less alone, depressed,	**Notes:**

	etc; feeling more ready to start dialysis, transplant; having fewer or milder symptoms; having to go to hospital less frequently; living longer)	
	Now let's review the second persona we will be using. **Persona 2: Caring Cory** - Cory is a retired 61-year-old who takes care of his wife who has glomerulonephritis. He's finding it difficult taking on the role of caregiver as his wife did these tasks before. He would like to connect with other caregivers, particularly men who are caring for a family member with CKD.	
	Persona 2: 1. (a) What would be the best method for ________ (persona) to **find out** about peer support? (e.g. directly from CKD staff, brochures, during education sessions) (b) When would be a **good time** for _________ (persona) to be introduced to peer support? Why? (e.g. start of CKD clinic, when pts need additional support) 2. How could _________ (persona) most easily **access** peer support? (e.g., referral process, ps integrated into CKD clinic, ps integrated into another self-management tool) 3. What would make a peer support program **successful** for (persona)? (e.g., having on-going access to a source of experiential knowledge; feeling less alone, depressed, etc; feeling more ready to start dialysis,	**Notes:**

	transplant; having fewer or milder symptoms; having to go to hospital less frequently; living longer)	

Appendix 4. Peer support consensus workshop evaluation

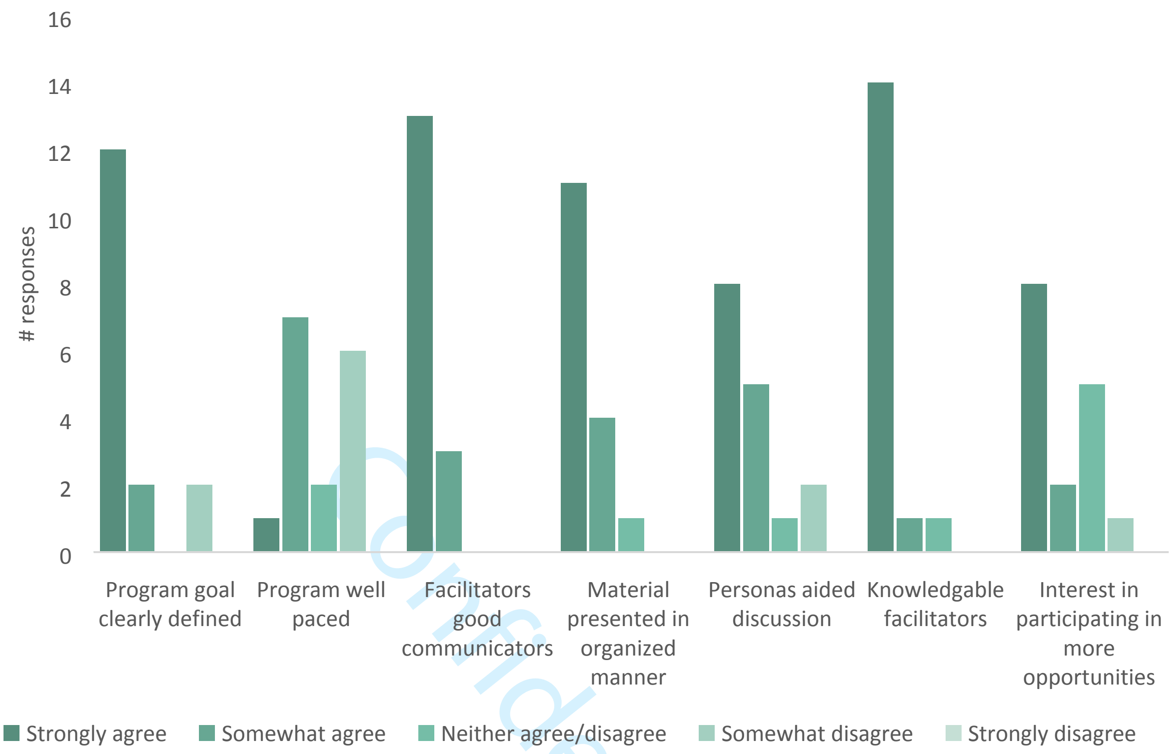
	Strongly agree				Strongly disagree
	1	2	3	4	5
1. The goal of the workshop was described clearly.	☐	☐	☐	☐	☐
2. The program was well paced within the allotted time.	☐	☐	☐	☐	☐
3. The facilitators were good communicators.	☐	☐	☐	☐	☐
4. The material was presented in an organized manner.	☐	☐	☐	☐	☐
5. The personas aided the topic discussion.	☐	☐	☐	☐	☐
6. The facilitators were knowledgeable on the topic.	☐	☐	☐	☐	☐
7. I would be interested in participating in more opportunities like this.	☐	☐	☐	☐	☐

8. Given the objectives, this workshop was: ☐ Too short ☐ Right length ☐ Too long

9. Please rate the following:	Excellent	Very good	Good	Fair	Poor
a. Visuals	☐	☐	☐	☐	☐
b. Workshop organization	☐	☐	☐	☐	☐
c. Virtual platform	☐	☐	☐	☐	☐
d. The workshop overall	☐	☐	☐	☐	☐

10. What did you most appreciate/enjoy/think was best about the workshop? Any suggestions for improvement?

Summary of Findings: Sixteen of 21 participants completed the evaluation. The following graphs report participant responses to evaluation questions:



Ten participants (63%) reported that the workshop was too short, 5 (31%) stated that it was the right length, and one (6%) thought it was too long. Several participants provided text-based feedback that the volume of material was too large to be covered in the allotted time and suggested either a longer session or two shorter sessions.