Determining preferences for a self-management eHealth tool for patients with chronic kidney disease: a patient-oriented consensus workshop using personas

Methods: Patients, caregivers and clinicians (n=24) across Canada participated in a 1-day consensus workshop. Using personas (fictional characters) and a cumulative voting technique they identified preferences for content for eight pre-determined topics and eHealth tool features. A patient-oriented research approach was taken with six patient partners involved in study design (i.e. co-planning workshop and materials), data collection (i.e. study participants at workshop) and review of results.

Results: Specific content for the eight pre-determined topics included: understanding CKD (information about kidneys, CKD and disease progression); diet (reliable information on diet for CKD and comorbidities, renal friendly foods); finances (affordability of medication, equipment, food, financial resources and planning); medication (common medications, side effects, indications, cost and coverage); symptoms (types, management); travel (limitations, insurance, access to healthcare, travel checklists); mental/physical support (screening and supports to address mental health, cultural sensitivity, adjusting to new normal); and work/school (support to integrate, restrictions). Preferred features included visuals, ability to enter and track health information, ability to interact with HCPs, "on-the-go" access, links to resources, and access to personal health information.

Interpretation: A consensus workshop developed around personas was successful for identifying detailed subject matter for eight pre-determined topic areas, as well as preferred features to consider in the co-development of a CKD patient self-management eHealth tool.

SCHOLARONE™
Manuscripts

GRIPP 2 checklist

Section and topic	Item	Reported on page No.
1. Aim	Report the aim of PPI in study.	7
2. Methods	Provide a clear description of the methods used for PPI in the study.	7 - 9
3. Study results	Outcomes – report the results of the PPI in the study, including positive and negative outcomes.	11 – 13, 15
4. Discussion and conclusions	Outcomes – comment on the extent to which PPI influenced the study overall. Describe the positive and negative effects.	12 - 15
5. Reflections/critical perspective	Comment critically on the study, reflecting on the things that went well and those that did not, so others can learn from this experience.	14 - 15

PPI = Patient and Public Involvement

Determining preferences for a self-management eHealth tool for patients with chronic kidney disease: a patient-oriented consensus workshop using personas

Authorship: Maoliosa Donald, MSc[1,2,3], Heather Beanlands, PhD[4], Sharon Straus, MSc, MD[5,6], Paul Ronksley, PhD[2,3], Helen Tam-Tham, PhD[1], Juli Finlay, PhD[1], Michelle Smekal, BSc[1], Meghan J. Elliott, MSc MD[1,2,3], Janine Farragher, PhD[1], Gwen Herrington MSc[7], Lori Harwood, PhD[8], Chantel A. Large, MSW[7], Claire L. Large, MSW[7], Blair Waldvogel, MBA[7], Maria Delgado[7,] Dwight Sparkes, BSc[7], Allison Tong, PhD[9], Allan Grill, MD[10], Marta Novak, PhD, MD[11], Matthew T. James, PhD, MD[1, 2], K. Scott Brimble, MSc, MD[12], Susan Samuel, MSc, MD[13], Karen Tu, MSc, MD[10], Brenda R. Hemmelgarn, PhD MD[1,2,3]

Affiliations:

[1] Department of Medicine, University of Calgary, Calgary, Alberta, Canada
[2] Interdisciplinary Chronic Disease Collaboration, Calgary, Alberta, Canada
[3] Department of Community Health Sciences, University of Calgary, Calgary, Alberta, Canada
[4] Daphne Cockwell School of Nursing, Ryerson University, Toronto, Ontario, Canada
[5] Department of Medicine, University of Toronto, Toronto, Ontario, Canada
[6] Li Ka Shing Knowledge Institute, St. Michael's Hospital, Toronto, Ontario, Canada
[7] Can-SOLVE CKD Patient Partner, Vancouver, British Columbia, Canada
[8] London Health Sciences Centre, London, Ontario, Canada
[9] Sydney School of Public Health, The University of Sydney, Sydney, New South Wales, Australia
[10] Department of Family & Community Medicine, University of Toronto, Ontario, Canada
[11] Centre for Mental Health, University Health Network and Department of Psychiatry, University of Toronto, Toronto, Ontario, Canada
[12] Department of Medicine, McMaster University, Hamilton, Ontario, Canada
[13] Department of Pediatrics, University of Calgary, Calgary, Alberta, Canada

Corresponding author's address:

Dr. Brenda R Hemmelgarn, MD, PhD, FRCPC
Cumming School of Medicine, University of Calgary
TRW Building, 3rd Floor
3280 Hospital Drive NW
Calgary, AB Canada T2N 4Z6
Phone: 403-210-7065
Fax: (403) 210-9286
Email: Brenda.Hemmelgarn@ahs.ca

1

Abstract word count: 250

Manuscript word count): 2493

Short title: Preferences for a CKD patient self-management eHealth tool

2

ABSTRACT

Background: Electronic health (eHealth) tools may support patients' self-management of chronic kidney disease (CKD). We aimed to identify preferences of CKD patients, caregivers and health care providers (HCPs) regarding content and features for an eHealth tool to support CKD self-management.

Methods: Patients, caregivers and clinicians (n=24) across Canada participated in a 1-day consensus workshop. Using personas (fictional characters) and a cumulative voting technique they identified preferences for content for eight pre-determined topics and eHealth tool features. A patient-oriented research approach was taken with six patient partners involved in study design (i.e. co-planning workshop and materials), data collection (i.e. study participants at workshop) and review of results.

Results: Specific content for the eight pre-determined topics included: understanding CKD (information about kidneys, CKD and disease progression); diet (reliable information on diet for CKD and comorbidities, renal friendly foods); finances (affordability of medication, equipment, food, financial resources and planning); medication (common medications, side effects, indications, cost and coverage); symptoms (types, management); travel (limitations, insurance, access to healthcare, travel checklists); mental/physical support (screening and supports to address mental health, cultural sensitivity, adjusting to new normal); and work/school (support to integrate, restrictions). Preferred features included visuals, ability to enter and track health information, ability to interact with HCPs, "on-the-go" access, links to resources, and access to personal health information.

3

Interpretation: A consensus workshop developed around personas was successful for

identifying detailed subject matter for eight pre-determined topic areas, as well as preferred

features to consider in the co-development of a CKD patient self-management eHealth tool.

Index words: Chronic kidney disease, patient-oriented research, person-centered care, personas,

self-management

4

Plain Language Summary

Electronic health (eHealth) tools such as websites and mobile applications may help patients

with chronic kidney disease (CKD) and caregivers manage their health and well-being. In this

study, we identify the preferences of patients with CKD, caregivers and health care providers

regarding content and features for an eHealth tool to support self-management of CKD. Our

study team included six patient partners as well as researchers, clinicians and decision makers.

Our patient partners were involved in all phases of the research.

We invited patients, caregivers, researchers and health care providers to discuss content

preferences for eight pre-determined topics, as well as features for an eHealth tool. Participants

wanted access to general and concise information about: the kidneys, CKD and disease

progression; diet requirements for CKD and other comorbidities; affordable food, medication,

financial resources and planning; reasons for and side-effects of medications; symptom

management; travel limitations and insurance; mental health screening and supports; and

work/school guidance. Patients and caregivers wanted eHealth features that can be accessed "on-

the-go", display information visually, have the ability to enter and track health information,

interact with health care providers, and provide links to resources. These findings will help guide

co-development of an eHealth tool for self-management for patients with CKD and caregivers.

5

INTRODUCTION

The focus on person-centered care has prompted changes in patient engagement in their health, as well as their contribution in research. Patients with chronic kidney disease (CKD) and those that care for them embark on a lifelong journey that entails dealing with complex medical issues and balancing medical management of kidney disease with demands of their daily lives. For the approximately 9% of Canadian adults living with CKD these issues often include management of diabetes, high blood pressure and cardiovascular disease, and strategies to slow progression of their CKD to delay or avoid development of end-stage kidney disease (ESKD).[1] The unique expertise that patients with CKD develop in managing their illness is recognized as invaluable to the research processes.

A national research priority setting project involving patients, caregivers and stakeholders identified the need to enhance patient-targeted strategies for self-managing CKD.[2] Self-management, a complex set of processes that involves acquiring knowledge, skills and confidence to manage a chronic disease[3], has the potential to positively impact clinical outcomes and quality of life for patients with CKD.[4] There is the opportunity to involve patients in the development of self-management support interventions that meet their needs, specifically around the areas of knowledge, how they receive it and timeliness of the information.[5] Traditionally, self-management interventions for patients with CKD include education and support through face-to-face interactions with minimal use of electronic health tools (e.g., websites, mobile apps, short messaging service).[6] The use of an electronic health (eHealth) tool, including the Internet, mobile phone-based applications, computer based and mixed modes, may enhance patient self-management,[7] given the increased use of the Internet by individuals with chronic disease as a

6

"first stop" for health information.[8] While eHealth tools will not replace the provider-patient relationship, they are a potential platform to augment CKD self-management support.

This study is part of a national multi-phase project involving patients, caregivers, health care providers (HCPs), researchers and policy makers (Canadians Seeking Solutions and Innovations to Overcome CKD, Can-SOLVE CKD Network).[9] Prior work included a qualitative study exploring the needs of adults with CKD and caregivers for self-management support.[5] Eight topic areas were identified (understanding CKD, diet, medications, symptoms, finances, mental/physical health, travel, and work/school), as well as features including mixed content formats (e.g. visuals, text, user generated content, etc.). In this paper we describe a consensus workshop using personas and engagement of our patient and caregiver partners (i.e. from herein Patient Partners, PP) to determine preferences for content for the eight pre-determined topic areas and features for a CKD patient self-management eHealth tool.

METHODS

Study design

We used a 1-day consensus workshop format to engage stakeholders in identifying content preferences for eight pre-determined topic areas and features for a CKD patient self-management eHealth tool. The workshop comprised a combination of small and large group exercises, using personas, facilitated by individuals with experience in group facilitation techniques. A cumulative voting technique (i.e. dot democracy)[10] approach was used in the final phase of the workshop where participants used dots to delineate their preferences. We used the Guidance for Reporting Involvement of Patients and Public (GRIPP2) to report this work.[11]

7

Persona Co-creation

Personas are fictitious descriptions of users that facilitate and guide the creation of interactive

systems, and have been used in the fields of human-computer interaction and marketing.[12] For

the purpose of our workshop, personas were used to represent hypothetical patients with CKD

and caregivers, with the aim of improving communication about their needs to stakeholders. We

developed the personas as an archetypical representation of real and potential eHealth tool users,

to illustrate their characteristics (e.g. needs, skills, behaviors, motivations, frustrations and

goals). The general principles of persona development include the use of empirical evidence

(quantitative and qualitative data), the concept of "particularity" (i.e. user characteristics and

behaviors) and using a collaborative approach with engagement of relevant stakeholders.[12, 13]

Figure 1 represents the multi-step process used for co-creation of the six personas (three patients

and three caregivers). We initially created a persona skeleton to include the following

components: persona name, demographic description (e.g. age, diagnosis, hobbies, life

experiences, etc.), goals (e.g. lifestyle) and challenges (e.g. frustrations, concerns). Next, we used

data from our prior work to populate persona templates, including age, gender, CKD category

and comorbidities.[5, 14] In consultation with our six PPs, using an iterative process, persona

features were modified including persona names, goals, challenges, technical ability (i.e.

computer literacy, internet use/availability) and health behavior characteristics (i.e. health

literacy, support networks, knowledge of health status, readiness for change). Revised personas

were reviewed at an in-person research team meeting and through discussion and agreement, the

six personas were finalized. General comments from our PPs regarding persona co-creation

included "I felt I could give meaningful input and be involved in this step of the research" and

8

"we had the opportunity to make them (personas) real – persona-fying my experience". An

example of a patient persona is provided in Appendix 1, Supplementary.

Participants and Setting

English-speaking individuals, aged 18 years or over, who were able to provide informed consent

and aware of their diagnosis of CKD (Categories 1 to 5, not on dialysis), regardless of CKD

etiology or duration, were eligible to participate in the workshop. Informal caregivers (e.g.

family members, friends) of individuals with CKD, researchers, clinicians and policy makers

with an interest in CKD care were also eligible. Through email invitation, participants were

recruited from the Can-SOLVE CKD Network[9] as well as prior focus group and interview

participants[5] who provided consent to be contacted for future phases of this work. We

purposefully sampled to ensure we had diversity from all stakeholder groups. Two weeks prior to

the consensus workshop, participants received materials including a Reflective Questionnaire

(Appendix 2, Supplementary) and were asked to reflect on their personal experiences with CKD

based on their stakeholder roles. This was done to capture their individual self-management

preferences, prior to asking them to take on a persona perspective at the workshop.

Data Collection

At the beginning of the workshop, the main facilitator (MD) presented background information

including results from a scoping review of CKD self-management support interventions[14], a

survey of Canadian CKD clinics to identify their resources used[6] and findings of a qualitative

study of patients with CKD and caregiver self-management needs.[5] Facilitators moderated four

9

heterogeneous small groups (i.e. representatives from all stakeholder groups) using a discussion guide (Appendix 3, Supplementary), directing participants to assume a persona lens and provide input regarding the persona's needs for each topic area and feature category. Small group discussions were captured by a note taker as well as audio recorded. Small group discussions were followed by a large group discussion where a representative from each group provided a summary of group ideas. Subject matter from small and large group discussions were recorded and categorized on flip charts by the facilitators under each of the eight pre-determined topic areas and general eHealth features. Cumulative dot voting (i.e. dot democracy) was used to identify preferences for content and features. Each participant was provided with 5 dots to vote on 5 individual content ideas/suggestions under each of the eight pre-determined topic areas, and 3 dots for each of the feature categories, which they considered "important to people with CKD and those that care for them". All participants completed an evaluation at the end of the workshop (Appendix 4).

Patient Engagement

Six PPs (GH, CAL, CLL, BW, MLD, DS) from across Canada are collaborators on the CKD self-management research team: one is a caregiver and five are patients with CKD. The PPs were involved in the study design (i.e. co-planning consensus workshop and materials), participated in data collection (i.e. study participants at consensus workshop), reviewed final outputs, and contributed to manuscript preparation and dissemination (i.e. conferences).

10

Statistical Analysis

Descriptive analysis was used for demographic and workshop data. To rank preferences for each of the content suggestions under the eight pre-determined topic areas and general features, dots were tallied and content ideas were ranked as high (≥10 dots), medium (3- 9 dots) and low (< 3 dots) priority. To ensure all subject matter was captured, two team members (BH and MD) independently reviewed the list of preferences, reflective questionnaire responses, field notes and flip chart data. Next, the two team members reviewed and finalized the wording for the content suggestions for the eight pre-determined topic areas and general features.

Four weeks following the workshop, participants were provided the results and were offered the opportunity to provide feedback via email. Respondent comments validated the findings with no changes required.

Ethics approval

Ethics approval was obtained from the University of Calgary Conjoint Health Research Ethics Board (REB17-0908). Participants provided written informed consent prior to participating.

RESULTS

Workshop

The workshop included 24 participants (11 patients, 6 caregivers, 2 nurses and one dietitian, pharmacist, policy maker, primary care physician and nephrologist) from across Canada. The majority of participants were female (80%), under the age of 65 years (84%), married (63%),

11

employed (79%) with a minimum of a post-secondary education (88%) and living in an urban

setting (63%) (Table 1). The majority of patient participants had an estimated Glomerular

Filtration Rate (eGFR) of greater than 15 mL/min/1.73 m^2 (73%), and were diagnosed within the

last 10 years (74%).

Within the eight pre-determined topic areas, the following content suggestions were ranked the

highest (≥ 10 dots): understanding CKD (basic information about kidneys, CKD and disease

progression); diet (reliable information on diet requirements for CKD and other comorbidities,

renal friendly foods); finances (affordability of medication, equipment, food, financial resources

and planning); medication (common medications, side effects, indications, cost and coverage);

symptoms (types, management); travel (limitations, insurance, access to healthcare, travel

checklists); mental/physical support (screening and supports to address mental health, cultural

sensitivity, adjusting to new normal); and work/school (support to help integrate, restrictions)

(Table 2).

Generally, participants indicated that the eHealth tool should be interactive with multi-media (i.e.

text, images, graphics, etc.) components. Preferred features included visuals, ability to enter and

track health information and interact with HCPs, on-the-go access, links to resources, and access

to personal health information. In the large group discussion there was support for features that

were ranked as medium priority. These included a matrix visual (i.e. set of cells that contain

visual and textual elements for users to choose from) versus a list of topics, as well as a layering

12

feature where they can "drill down for specifics" (i.e. go step by step through content based on their needs).

Workshop evaluation

All participants completed the post-workshop evaluation. The majority (> 95%) strongly agreed that the workshop goal was clear, the material was well organized and the facilitators were knowledgeable. Twenty-three participants (96%) strongly agreed that the personas aided in topic discussions. Participant comments included "personas great because I related with all of them", "personas, excellent way to focus the conversations and gain multiple perspectives" and "personas were great in aiding with workshop objectives".

INTERPRETATION

Our patient-oriented research (POR) study demonstrated how PPs are able to provide important input to study processes. This input included the creation of personas to engage stakeholders at a consensus workshop, and the use of those personas to determine preferences for content and features for a CKD patient self-management eHealth tool. Through the consensus workshop, we were able to identify key subject matter for eight pre-determined topic areas relevant for CKD self-management, as well as feature elements for an eHealth tool.

To our knowledge, there is limited literature on the co-creation of personas with PPs for health research. The persona-based methodology has been described in medical informatics literature[13]

13

and has been studied by a handful of health researchers.[15, 16] These studies suggest that personas are useful in informing the design and implementation of health technologies. Using a multi-method structured approach including PPs and research team members in all aspects of this project enabled us to capture and present the broad self-management needs for both patients and caregivers. The six multi-dimensional personas allowed participants to critically reflect on how patients with CKD or caregivers think, feel and behave. In the context of self-management, the personas demonstrated life complexities for both patients and caregivers, along with issues that determine an individual's ability to engage in managing CKD and living life with a chronic disease. In the workshop, the personas were an effective tool to advocate for patients and caregivers, facilitate communication between workshop participants, and provide rich descriptions of otherwise complex scenarios in order to prioritize content and features for an eHealth tool.

The consensus workshop allowed us to capture unique details around the broad topic areas to support CKD self-management and identify preliminary features for an eHealth tool. Compared to other techniques (i.e. focus groups, surveys) the dot democracy (voting) approach was efficient and created a receptive environment enabling all workshop participants to participate equally. The content identified for each topic area are similar to those from prior literature reviews, including information about understanding CKD, medications, lifestyle modification and dietary advice.[17, 18] We also considered additional needs that patients and caregivers have identified as important for self-management[5] including travel, work/school, finances, symptoms, mental and physical support, as well as features of an eHealth tool. Through the consensus

14

workshop we were able to delve into specifics for each of these areas and identify preferences for information and resources that should be considered.

Limitations

Our findings should be interpreted within the context of our study population. The majority of participants were recruited through the Can-SOLVE CKD Network and were past participants from our previous studies, suggesting that they may be more engaged in self-management. In addition, participants needed to be English speaking to participate in the workshop, and the majority were female with post-secondary education, therefore our findings may not be reflective of the preferences of the broader population of patients with CKD and those that care for them.

Lessons learned from patient engagement

Our findings are grounded in the experiences of our PPs, with varying levels of lived experience with CKD as well as knowledge and skills with research-related activities. We used strategies and contextual factors to ensure that PPs experiences, skills, flexibility and availability were included. Our PPs have been involved in the research processes of previous studies for this multi-phase research project, ensuring that they were integral in decision making along the way. Meaningful recognition through shared power (GH, PP co-principle investigator) and meaningful collaboration through face-to-face team meetings and informal talks one-on-one were fundamental to mutual learnings. Ultimately, PP engagement will continue to inform this multi-phase project to ensure a positive impact on the quality of life and health care for patients living with CKD.

15

Conclusions

Our study illustrates success using personas in a consensus workshop to determine preferences

for content and features of an eHealth tool for CKD self-management. The use of personas could

be applied to other applications in other POR work exploring patient preferences and needs in

order to improve care and relevant outcomes. These findings will inform further co-development

of a CKD patient self-management eHealth tool through continued patient engagement.

CONTRIBUTORS

Research idea and study design: all authors; data acquisition: MD, BH, ME, JF, HT; data

analysis/interpretation: MD, BH. Each author contributed important intellectual content during

manuscript drafting and revisions and accepts accountability for the overall work by ensuring

that questions to the accuracy or integrity of any portion of the work are appropriately

investigated and resolved. All authors read and approved the manuscript and agreed to act as

guarantors of the work.

FUNDING

16

ACKNOWLEDGEMENTS

We thank the patients, caregivers and health care providers from across Canada who participated

in the study. We would also like to thank the individuals who assisted in various study related

activities: Sarah Gil and Sarah Baay.

COMPETING INTERESTS

None declared.

FINANCIAL DISCLOSURES

The authors declare that they have no relevant financial interests.

17

CMAJ Open Manuscript

REFERENCES

1.	G. B. D. Disease Injury IP, Collaborators. Global, regional, and national incidence, prevalence, and years lived with disability for 354 diseases and injuries for 195 countries and territories, 1990-2017: a systematic analysis for the Global Burden of Disease Study 2017. *Lancet*. 2018; 392: 1789-858.
2.	Hemmelgarn BR, Pannu N, Ahmed SB, et al. Determining the research priorities for patients with chronic kidney disease not on dialysis. *Nephrol Dial Transplant*. 2017; 32: 847-54.
3.	Lorig KR and Holman H. Self-management education: history, definition, outcomes, and mechanisms. *Ann Behav Med*. 2003; 26: 1-7.
4.	Havas K, Douglas C and Bonner A. Meeting patients where they are: improving outcomes in early chronic kidney disease with tailored self-management support (the CKD-SMS study). *BMC Nephrol*. 2018; 19: 279.
5.	Donald M, Beanlands H, Straus S, et al. Identifying needs for self-management interventions in patients with chronic kidney disease and their caregivers: a qualitative study. *AJKD*. 2019; In Press.
6.	Donald M, Gil S, Kahlon B, et al. Overview of Self-Management Resources Used by Canadian Chronic Kidney Disease Clinics: A National Survey. *Can J Kidney Health Dis*. 2018; 5: 2054358118775098.
7.	Stevenson J, Campbell Z, Webster A, Chow C, Campbell K and Lee V. eHealth interventions for people with chronic kidney disease. *Cochrane Database of Systematic Reviews*. 2016.
8.	Stellefson M, Chaney B, Barry AE, et al. Web 2.0 chronic disease self-management for older adults: a systematic review. *J Med Internet Res*. 2013; 15: e35.
9.	Levin A, Adams E, Barrett BJ, et al. Canadians Seeking Solutions and Innovations to Overcome Chronic Kidney Disease (Can-SOLVE CKD): Form and Function. *Can J Kidney Health Dis*. 2018; 5: 2054358117749530.
10.	Wikipedia. Dot-voting.[Internet]. 2018 [Accessed: 2019, February 11]. Available from: https://en.wikipedia.org/wiki/Dot-voting.
11.	Staniszewska S, Brett J, Simera I, et al. GRIPP2 reporting checklists: tools to improve reporting of patient and public involvement in research. *Bmj-Brit Med J*. 2017; 358.
12.	Miaskiewicz T and Kozar KA. Personas and user-centered design: How can personas benefit product design processes? *Design Stud*. 2011; 32: 417-30.
13.	LeRouge C, Ma J, Sneha S and Tolle K. User profiles and personas in the design and development of consumer health technologies. *Int J Med Inform*. 2013; 82: e251-68.
14.	Donald M, Kahlon BK, Beanlands H, et al. Self-management interventions for adults with chronic kidney disease: a scoping review. *BMJ Open*. 2018; 8: e019814.
15.	Vosbergen S, Mulder-Wiggers JM, Lacroix JP, et al. Using personas to tailor educational messages to the preferences of coronary heart disease patients. *J Biomed Inform*. 2015; 53: 100-12.
16.	Valaitis R, Longaphy J, Nair K, et al. Persona-scenario exercise for codesigning primary care interventions. *Can Fam Physician*. 2014; 60: 294-6.
17.	Lopez-Vargas PA, Tong A, Howell M and Craig JC. Educational Interventions for Patients With CKD: A Systematic Review. *Am J Kidney Dis*. 2016; 68: 353-70.
18.	Havas K, Bonner A and Douglas C. Self-management support for people with chronic kidney disease: Patient perspectives. *Journal of renal care*. 2016; 42: 7-14.

18

CMAJ Open Manuscript

19

Table 1. Participant characteristics

Participant Characteristics (n=24)	Number (%)
Role	
Patient	11 (46)
Caregiver	6 (25)
Health care professional (2 nurses, dietitian, pharmacist, PCP, nephrologist, decision maker)	7 (29)
Gender	
Male	5 (20)
Female	19 (80)
Age (years)	
Under 50	11 (46)
50 – 64	9 (38)
65 – 74	3 (12)
≥ 75	1 (4)
Marital status	
Common Law	5 (21)
Divorced	2 (8)
Married	15 (63)
Single	2 (8)
Geographical location (Population)	
< 500,000 (rural)	9 (37)
≥ 500,000 (urban)	15 (63)
Level of education	
Primary (≤ grade 12)	3 (12)
Post-secondary (college, university, trade school)	12 (50)
Graduate	9 (38)
Level of employment	
Full-time	11 (46)
Part-time	8 (33)
Retired	4 (17)
Student	1 (4)
Self-reported Patient Clinical Characteristics (n=11)	
Duration of CKD diagnosis (years)	
≤ 5	5 (46)
6 – 10	2 (18)
≥ 11	4 (36)
Severity of CKD [eGFR (mL/min/1.73 m^2)]	
30 – 60	5 (46)
15 – 29	3 (27)
<15	1 (9)
Unknown	2 (18)

CKD = chronic kidney disease; eGFR = estimated Glomerular Filtration Rate; PCP = primary care physician

Table 2. CKD self-management topic and feature areas with content suggestions and corresponding counts

Topic area*	Priority	Content Suggestions	Counts
Understanding CKD	**High**	Basic information about CKD: • What causes CKD • Impact of CKD and how to manage it (lifestyle, wellbeing) • How to assess risk of progression • Understanding eGFR	20
		Basic information about kidneys and what they do	17
		How to slow progression	15
	Medium	Where to find credible and reliable information on CKD	5
	Low	How to prevent CKD	2
		Timing of symptoms in relation to CKD progression	1
		Learning new skills to manage CKD	1
		Fertility and family planning	0
Diet	**High**	Reliable information on diet and nutritional requirements	18
		Dietary changes required for CKD and other comorbidities (e.g. diabetes)	17
		Renal friendly/unfriendly foods (e.g. what to eat/not to eat)	15
	Medium	How to read food labels	7
		Meal planning (e.g. how to make modifications)	7
	Low	Diet tracking tools	2
		How to identify renal friendly food that is affordable	2
		Cooking classes	0
Symptoms	**High**	How to manage symptoms and when to seek help	18
		What are the symptoms of CKD, what causes them, what to expect as CKD progresses	14
		When to act on symptoms, severity of symptoms	12
		Considerations for other comorbidities and impact of treatment for other conditions	11
	Medium	Fatigue	6
		Symptom expectations	6
	Low	How to slow progression of symptoms	2
		Lack of symptoms (i.e. silent disease)	1
Medications	**High**	Common medications for CKD, side effects to watch for and how to manage	22
		Indications for medications	20
		Cost, coverage, insurance for medications	18
	Medium	Long term use of medications and implications	4

1

	Low	Medication interactions	3
		Interactions between Western and alternative therapies	2
		How to facilitate pill taking	0
		Medication diary	0
Mental & Physical Health	**High**	Recognition of mental health as a symptom of CKD	19
		Support for patients and broader circle (e.g. family, caregivers) for mental and physical wellness	13
		Recognition of cultural sensitivity	11
		Depression screening	10
		Addressing how to adjust to new "normal"	10
	Medium	Resources and support for mental health (e.g. anxiety, guilt, burden)	5
Finances	**High**	Affordability and accessibility of medications, equipment, food	23
		Financial coverage and resources	22
		Long term planning of finances	21
	Low	Budgeting	2
Travel	**High**	Travel limitations	18
		Travel insurance	17
		Accessing healthcare abroad	14
		What to bring on work/leisure trips	10
	Medium	Medications for travel/letter of support	7
		Travel to appointments and how to minimize travel burden	5
	Low	Support for caregiver travel	1
		Volunteer drivers and supported transit	1
Work & School	**High**	Accommodating work/school environment	18
		Integrating diet/medications into lifestyle (e.g. work and school environment)	16
		Supports and considerations for returning to work/school	15
		Restrictions for work/school	11
	Low	Arranging for respite	1
Features of eHealth tool	**High**	Pictures and visuals	15
		Ability to enter and track health information	13
		Accessible/on the go access to information	12
		Links to resources	12
		Interact virtually with health team	12
		Access to electronic personal health information	12
	Medium	Matrix style (i.e. ability to drill-down to more detailed information)	9
		Keep tool simple	9
		Build own profile	9

2

		Quick tips and tools	8
		Online chat group	8
		Caregiver section	7
		Multi-medium format (multiple features)	7
		Regular updates to tool	6
		Reminders, alerts	6
		Secure messaging	6
		Considerations for privacy	5
	Low	Multiple languages	4
		Mobile application	3
		Organize information by disease stage	3
		Acknowledge different sensory needs (e.g. visual, hearing)	2
		Reliable, credible information	2
		Ability to download or save content	2
		Searchable feature	2
		Personal/patient stories	2
		Consider stage of readiness to learn	2
		Virtual coach	2
		Tinder-like application	1
		Favorites option	1
		Print feature	1
		Forum to submit questions	1
		Filters	1
		Podcasts/audio files	1
		Hierarchical format	0
		Calendar sharing	0
		Decision aids	0
		Help feature (tool use training)	0

CKD = chronic kidney disease; eGFR = estimated Glomerular Filtration Rate
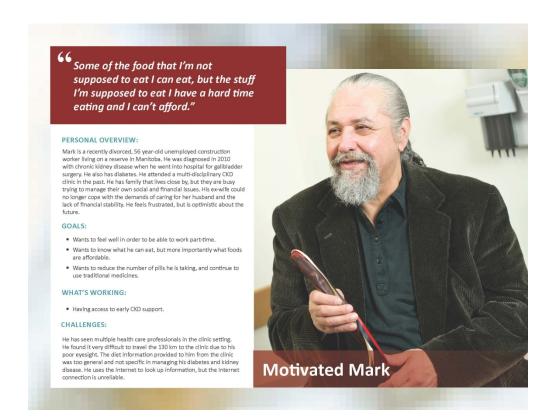
*Main topic areas not ranked

3

Figure 1. Persona co-creation process

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

> **"** *Some of the food that I'm not supposed to eat I can eat, but the stuff I'm supposed to eat I have a hard time eating and I can't afford."*

PERSONAL OVERVIEW:

Mark is a recently divorced, 56 year-old unemployed construction worker living on a reserve in Manitoba. He was diagnosed in 2010 with chronic kidney disease when he went into hospital for gallbladder surgery. He also has diabetes. He attended a multi-disciplinary CKD clinic in the past. He has family that lives close by, but they are busy trying to manage their own social and financial issues. His ex-wife could no longer cope with the demands of caring for her husband and the lack of financial stability. He feels frustrated, but is optimistic about the future.

GOALS:

- Wants to feel well in order to be able to work part-time.
- Wants to know what he can eat, but more importantly what foods are affordable.
- Wants to reduce the number of pills he is taking, and continue to use traditional medicines.

WHAT'S WORKING:

- Having access to early CKD support.

CHALLENGES:

He has seen multiple health care professionals in the clinic setting. He found it very difficult to travel the 130 km to the clinic due to his poor eyesight. The diet information provided to him from the clinic was too general and not specific in managing his diabetes and kidney disease. He uses the Internet to look up information, but the Internet connection is unreliable.

Motivated Mark

279x215mm (200 x 200 DPI)

ENHANCING CKD SELF-MANAGEMENT WORKSHOP

PERSONAL EXPERIENCE WITH CKD SELF-MANAGEMENT

We would like you to think about and consider your own experience as it relates to your role as either a patient, caregiver, health care provider, or policy maker in self-managing CKD.

What questions would you have regarding managing and/or understanding any of the following: CKD, finances, symptoms, medication, work/school , travel, diet, mental and physical health?

What would be the best way of providing information regarding CKD topics and resources?

Please provide a brief response below to the above questions.

Donald, et al, "Determining preferences for a self-management eHealth tool for patients with chronic kidney disease: a patient-oriented consensus workshop using personas"

CKD self-management eHealth tool content

What questions/information would _____ (**patient persona/caregiver persona**) have around (or be seeking) for:

- Understanding CKD (e.g. cause, risk factors, what kidneys do, signs/symptoms, treatment options, progression, complications, etc.)
- Diet (e.g. food labels, conflicting restrictions based on multi-morbidities, etc.)
- Medications (e.g. side effects, why prescribed, how to take, etc.)
- Symptoms (e.g. fatigue, medication side effects)
- Work/school (e.g. maintaining work/school)
- Travel (e.g. insurance)
- Mental/physical health (e.g. fear, acceptance of disease, stigma/amount, type of activity)
- Finances (e.g. cost of medications)

Who would _____ (**patient persona/caregiver persona**) approach (seek out) for more emotional, social, and/or psychological support (e.g. to address depression, coping, maintaining relationships, sustaining hobbies, etc.)?

Probe: health care provider, family member (e.g. spouse, son/daughter), friends, peers, community group, people with similar concerns, multiple people/groups?

What would emotional, social and/or psychological support look like for _____ (**patient persona/caregiver persona**)?
Probe: peer/buddy support, message boards, forums, etc.?

CKD self-management eHealth tool features

What features would _____ (**patient persona/caregiver persona**) like included in an eHealth tool?

OR

How would _____ (**patient persona/caregiver persona**) navigate an online tool/app?

Probe:
Would any of these features (show handouts) be appealing to _____ (**patient persona/caregiver persona**):
- Access to general education/information (e.g. regarding content topics – diet, medication, mental/physical health, etc.)
- Training/education (e.g. interactive modules)
- Checklists (e.g. questions to ask health care provider)
- Reminders/alerts (e.g. medication – timing, refill reminders; lifestyle goals – exercise reminders, appointment reminders, etc.)

1

Donald, et al, "Determining preferences for a self-management eHealth tool for patients with chronic kidney disease: a patient-oriented consensus workshop using personas"

- Monitoring - access to and/or record data (e.g. patient portal – see lab results, medication list, current diagnosis, BP, etc.)
- Individualized information (e.g. custom information on diet for particular needs - CKD and diabetes; care planning – action/goal planning)
- Communication options – to communicate with health care providers, social networks, etc. (e.g. secure messaging, phone, online chat, etc.)

What format would _____ (**patient persona/caregiver persona**) want:
- Text
- Photos/pictures/graphs/etc.
- Print
- Video
- Social media
- Other (e.g. _____)

Multiple/hybrid methods

1
2
3
4
5
6
7
8
9
10
11
12
13
14
15
16
17
18
19
20
21
22
23
24
25
26
27
28
29
30
31
32
33
34
35
36
37
38
39
40
41
42
43
44
45
46
47
48
49
50
51
52
53
54
55
56
57
58
59
60

Enhancing CKD Self-management - Workshop Evaluation Form

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

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

9. Please rate the following:

		Excellent	Very Good	Good	Fair	Poor
a.	Visuals	❏	❏	❏	❏	❏
b.	Acoustics	❏	❏	❏	❏	❏
c.	Meeting space	❏	❏	❏	❏	❏
d.	Refreshments	❏	❏	❏	❏	❏
e.	Accommodations	❏	❏	❏	❏	❏
	(if stayed overnight)	❏	❏	❏	❏	❏
f.	Handouts	❏	❏	❏	❏	❏
g.	The program overall	❏	❏	❏	❏	❏

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

_____

_____

_____