

Patient-focused Self-management of CKD

Project Newsletter

Issue 6: Spring/Summer 2018



Accomplishments: April- June 2018

- Co-creation of personas for CKD self-management consensus workshop.
- In-person core committee meeting May 6th, 2018 in Vancouver, BC.
 - Members reviewed findings from focus groups and individual interviews.
 - Members provided suggestions to personas.
- CKD self-management consensus workshop held on June 13th, 2018 in Calgary, AB.

Next Steps:

- Prepare and publish manuscripts for phase 2 (qualitative study and workshop).
- Core committee meeting Fall 2018 to discuss next steps for eHealth tool co-design.

Workshop Summary: (24 participants)



- | | |
|--------------|-------------------------|
| 11 Patients | 1 Pharmacist |
| 6 Caregivers | 1 Policymaker |
| 2 Nurses | 1 Primary Care Provider |
| 1 Dietitian | 1 Nephrologist |

1. Topics:

Symptoms

What to do about symptoms?
What are the symptoms?
When to act on symptoms?

Emotional/Social & Psychological Support

Peer support
Cultural considerations/ethnic sensitivity (language, traditional medicines, etc.)
Access to mental health support

Understanding CKD

Impact of and how to manage CKD
Basic Information about CKD
Progression of CKD

Finances

Affordability and accessibility of medication and food
Financial coverage and resources
Long term financial planning

Diet

Where to find reliable information?
What changes will need to be made?
What to eat/not to eat?

Mental and Physical Health

Address mental health as a symptom of CKD (give equal weight)
Supports for patients and broader circle
Address cultural sensitivity regarding physical and mental health

Travel

Travel limitations
Travel insurance
Accessing healthcare abroad

Work/School

Accommodating work/school environment
Integrating diet/medications into lifestyle
Support with work/employment

Medication

Side effects
Medication purposes/reasons
Cost and coverage



2018 Workshop participants

“ Meeting and hearing different perspectives from patients, caregivers, health care providers.”

“ Loved the enthusiasm and the personas.”

2. Format:

- Pictures and visuals
- Accessible on-the-go
- Keep it simple

3. Features:

- Ability to enter/track health information
- Ability to interact virtually with healthcare team
- Links to relevant resources

