

Strategies to enhance patient self-management of chronic kidney disease (CKD): A multi-phase approach

Project journey: Adults with CKD and those that care for them have identified a need for a CKD self-management support intervention that can be individualized to a patient's unique situation, priorities and preferences to manage their disease and enhance their quality of life

Phase 1: (2016-17) **Discover** what exists for CKD self-management support

- Self-management CKD intervention scoping review**
- National CKD clinic survey**

Key findings: Lack of comprehensive information for CKD self-management, educational material primarily in written format, and lack of patient involvement in intervention development

** Published results, see handout

Phase 2 (2017-18) **Define** CKD self-management support preferences of patients and caregivers using personas

- Focus groups and telephone interviews
- National consensus workshop for an eHealth tool

Key findings: 8 content areas identified; symptoms, travel, work/school, finances, mental/physical health, diet, understanding CKD, and medication



“
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. He is well but 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 100 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

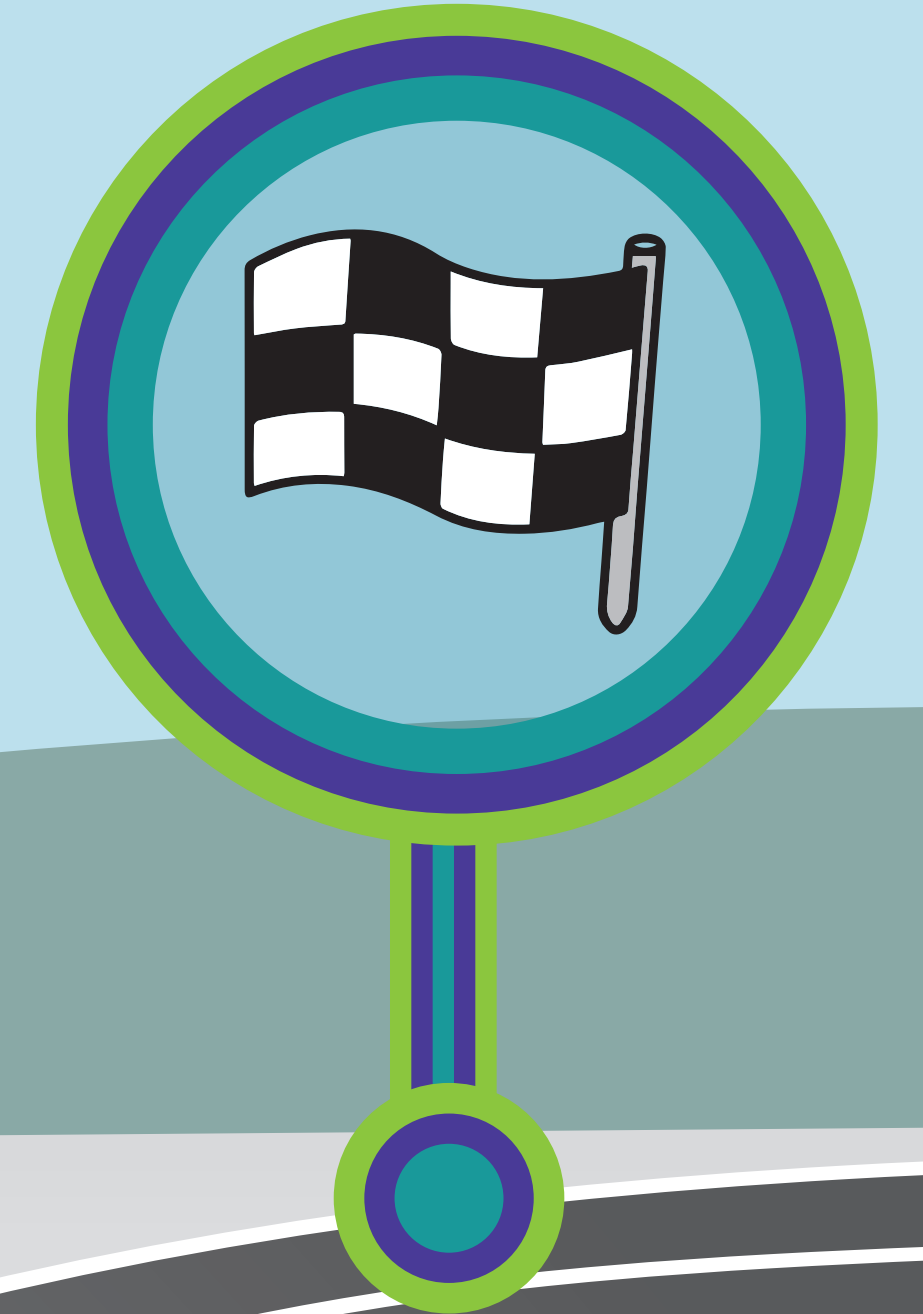
Persona example

Phase 3 (2018-19) **Develop** an electronic health (eHealth) tool

- CKD self-management website environmental scan (eScan)

Website eScan key findings: Website readability generally poor (grade 11+) and content areas identified in phase 2 were not available on most websites

- Co-develop content and features for an eHealth tool



Journey Endpoint

A novel, tailored CKD patient self-management web-based tool co-developed and tested by patients and caregivers



Phase 4 (2019-21) **Deliver** and evaluate the eHealth tool

- Coming soon

1. Inform & Consult

2. Involve & Collaborate

3. Lead & Empower

Ongoing Levels of Patient Engagement



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