

# Patient-focused Self-management of CKD Project Newsletter

Issue 12: Spring 2021



## Project updates:

### 1. Manuscript:

Our manuscript is published! "A web-based self-management support prototype for adults with chronic kidney disease (My Kidneys My Health): Co-design and usability testing" is available in JMIR Formative Research (<https://pubmed.ncbi.nlm.nih.gov/33560245/>)

### 2. Phase 4 - Feasibility study:

The aim of the feasibility study was to examine My Kidneys My Health website usage, participants satisfaction, any factors that may affect implementation, and seeing if it changes participant self-management behavior. The study participants had access to the website for 8-weeks. Recruitment started in June 2020 and was completed in Dec. 2020.

We had 32 participants enroll, with 22 participants complete the study. We have completed our analysis and these are some of the general findings.

- Participants had an overall higher level of self-efficacy (SE), the level of ability to cope. There was a significant change in one domain of SE, "SE to perform self-management behaviors – getting information about the disease" post website use.
- Acceptability of the website was rated high (agree, strongly agree) in the areas of usefulness, ease of use, and intention to use.
- Areas to consider for implementation and sustainability included opportunities to have pharmacists and primary care physicians promote website to patients with CKD.

### 3. Dissemination activities:

We would like to thank our research team members, KFOC, Can-SOLVE CKD Network, and many others for their assistance in launching My Kidneys My Health website in March. Some of the dissemination activities have included World Kidney Days, a poster presentation at WCN, and numerous social/news media platforms. We will continue to engage in dissemination activities, so please let us know of any relevant events or platforms.

### 4. Phase 5 planning - My Kidneys My Health implementation study:

The project aims to (1) identify problems that may prevent health care providers or clinics from recommending and using My Kidneys My Health website as be part of routine clinical care for individuals with CKD and (2) evaluate what worked, what did not work in order to better understand how to effectively scale-up usage in primary care and general nephrology clinic settings.

## Next Steps:

- Submit implementation study manuscript protocol for publication in May 2021.
- Mark your calendars for Can-SOLVE CKD Network Social Event on Thurs. June 3, 4:00 - 5:30 pm (MST)
- Initiate implementation study July 2021.

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## Meet Paul Watson, Patient Partner:

Recovering war reporter, now a writer. Married for 23 years; one son. Obsessed with disease progression, good or bad, best relieved by dinghy sailing.

Fun facts: Won a Pulitzer, a daily meditator who dreams of peace

I call polycystic kidney disease a yo-yo illness. My kidney function is up one month, down the next, raising hope only to dash it. When things seem to stabilize, related ailments send me spinning in yet another direction. Neuropathic pain is the worst. A dull ache suddenly shocks with a jolt so sharp it takes my breath away. I get strength from a medical team that never surrenders. They attack each new symptom as if it were the first, never telling me to just buck up and struggle through. That's why I think this is a fight I can win.



## Thank you!

We would like to thank Michelle for all the support she provided as a team member of the CKD self-management research group. We wish Michelle all the best in her new career as an independent research and evaluation consultant.

## The My Kidneys My Health Website is now Live!

As of March 11, 2020, My Kidneys My health website is live! Helping you discover kidney-friendly foods, manage your symptoms & mental wellness & so much more. To learn more about living well with kidney disease visit <https://mykidneysmyhealth.com>

Designed by patients for patients