

Adapting My Kidneys My Health to expand support for self-management

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Project overview

1 Implementation (complete)

Gap: Lack of self-management support for individuals living with non-dialysis kidney disease, and their caregivers.

Intervention: My Kidneys My Health, a website co-developed by patients, for patients with evidence-based content and tools to support living well with kidney disease.

Implementation: Website launched March 2021; implementation strategies mapped, developed, and launched 2023.

2 Adaptations (in progress)

Aim: Identify self-management gaps that address inclusion, diversity, equity, and accessibility (IDEA) to meet the needs of diverse populations.

Pillars of work to identify underprioritized areas of self-management:

1. Incorporating peer support resources
2. Supporting discussions around sexual health and kidney disease
3. Identifying and addressing needs of Indigenous communities

3 Future Activities

Adaptations: To support needs and enhance resources across 3 pillars of work.

Sustainability: To establish long-term plan to maintain the My Kidneys My Health website.



Year in review



Developed partnerships

- **Can-SOLVE project collaborations:** APPROACH, Kidney Check
 - Aligned efforts, shared resources
- **Experts:** C. Turner, S. Dumanski, C. McKeaveney
 - Enhanced quality and credibility of work, identified opportunities
- **Operations:** University of Calgary's Indigenous Research Support Team
 - Advised on ethical approach to Indigenous engagement & co-development



Expanded role of patient partners

- M. Loth and V. March brought their expertise in Indigenous engagement and led relationship building (e.g., in community, conferences)
- K. Ahrenholz brought lived experience into the interpretation of survey results about sexual health support in kidney disease
- Dissemination Working Group members provided their interpretation of website usage and strategic direction on dissemination and implementation



Began to identify gaps and needs, applying IDEA concepts

- **Peer support:** Identified existing programs and gaps
 - Considering how to increase accessibility
- **Sexual health:** Identified perceptions, practices, and gaps from healthcare providers' perspective
 - Inclusive language used, French survey option provided
- **Indigenous engagement:** Built team, developed approach to engagement and materials, making connections
 - Applied 6Rs of relationship building



Increased website accessibility

- Created "Resources" page to increase accessibility of materials, to house future materials developed
- Enhanced usability and accessibility of "My Questions List" feature based on feedback from Dissemination Working Group



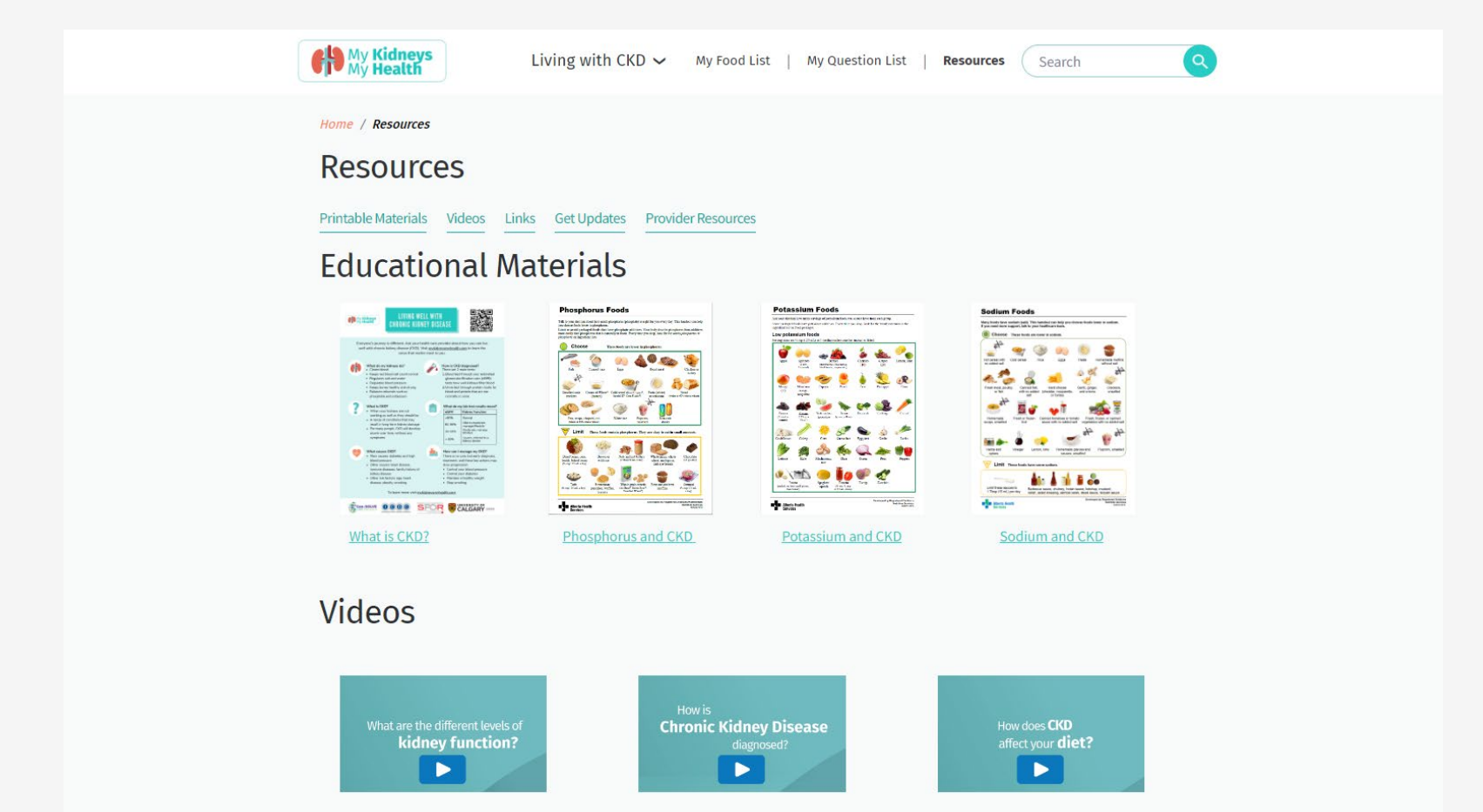
Self-Management & APPROACH teams



ML and VM speaking at NW SPOR Forum



Self-Management Team at Can-SOLVE AGM 2023



My Kidneys My Health – resources page update