

INTRODUCTION:

Successful self-management is an essential piece of optimal treatment of CKD, and a patients ability to implement these strategies has a significant impact on their health outcomes (1,2). One of the drivers of self-management is health literacy, so for patients with CKD, health literacy and health outcomes are intimately connected (3).

AIM:

We set out to explore the insights of experienced patient partners, looking at the importance of health literacy and how to target its improvement for newly diagnosed patients, in order to formulate a list of patient-led recommendations for future implementation.

METHODS:

Patient Oriented Research: Leadership from Patient Partners

Three patient partners co-led this project as integral members of the research team. They guided the project planning, facilitated the focus groups, and oversaw the thematic analysis of the data. Their contributions ensured that the patient voice was represented throughout.

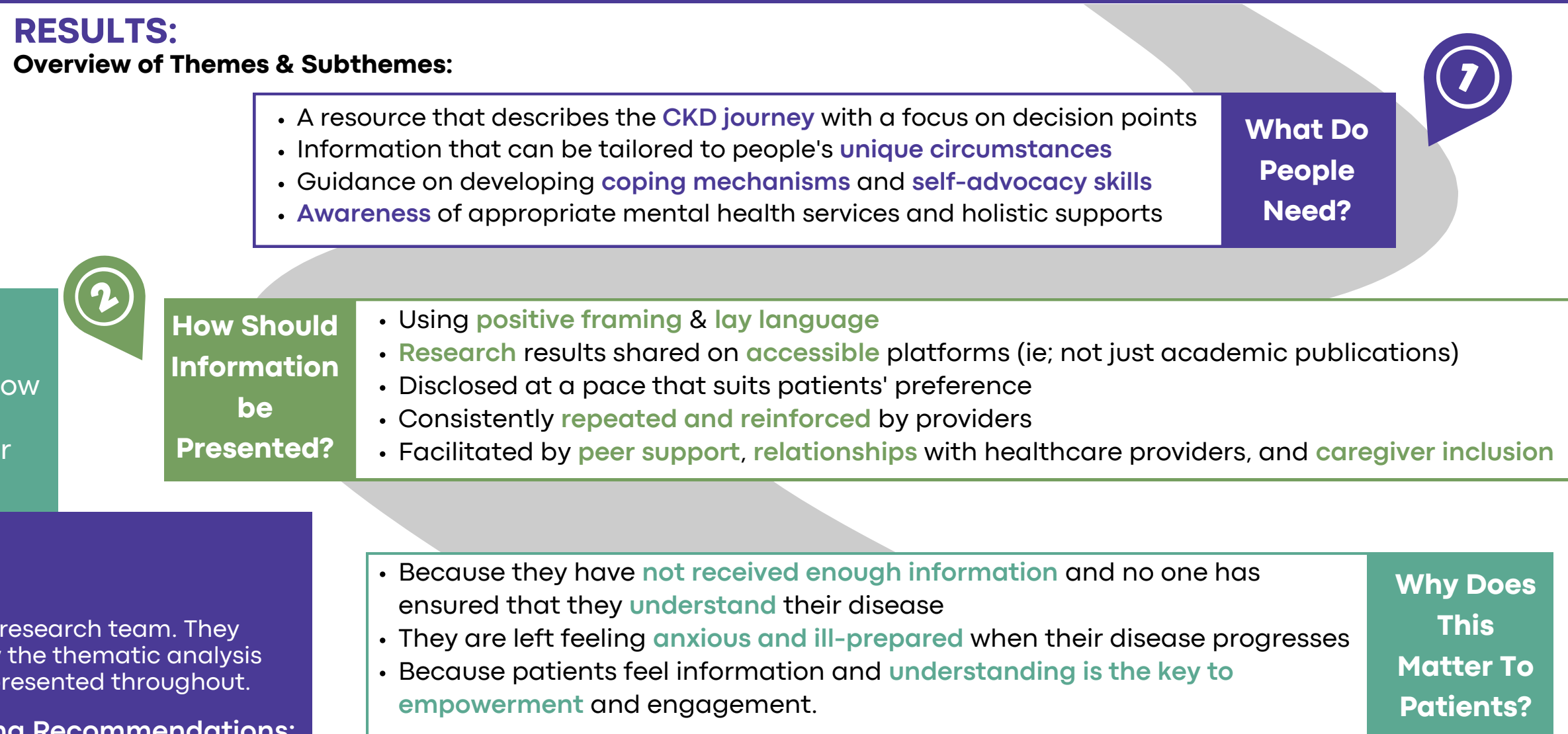
Process:

- Preliminary Planning**
Complete an environmental scan to understand the gaps in health literacy research Use purposeful sampling to recruit diverse pool of patient partners interested.
- In-Person Workshop**
Host & record in-person workshop with patient partners (n=14) using semi-structured focus groups and consensus collaboration to facilitate discussion.
- Analysis**
Transcribe and code transcripts using Delve software. Use an inductive, thematic analysis approach to illuminate themes and subthemes and relationships between them.

Developing Recommendations:

From the themes and sub-themes that were identified in step 3, we developed specific recommendations to initiate system-wide change to improve health literacy in patients with CKD.

By collecting insights from people with lived experience with CKD, our recommendations are informed by real-life experiences and rich knowledge.



CONCLUSIONS:

Addressing health literacy for people with CKD is essential to maximizing ability to manage and optimize health and must be prioritized by the health system. It is important to consider not just the creation of a resource for patients, but how this resource can be disseminated in a way that maximizes its utility and accessibility.

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Citations

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