

Anemia and CKD: Leveraging Patient Perspectives to Inform the Development of an Educational Toolkit

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Introduction

Anemia is associated with a lower health-related quality of life in CKD patients and 43.9% of people with CKD and anemia would like to receive more information on how to manage their anemia (1). This presents an opportunity for patient education, with the goal of empowering patients with CKD and their caregivers to engage in their care and effectively manage their anemia.

Aim

The purpose of the project is to host a series of focus groups to bring the patient and caregivers voice to issues affecting health and wellness related to anemia in chronic kidney disease (CKD). Based on the input from patient partners and focus group participants, Can-SOLVE CKD developed a patient toolkit to address the current gaps in knowledge and help patients feel informed and empowered enough to effectively manage their anemia and CKD.

Method

Recruited caregivers and patients with CKD and anemia to participate in our focus groups
Hosted three focus group sessions with a total of 17 participants
Created and released a follow-up survey for all participants
Qualitative data from the focus groups and survey were coded and analysed using grounded theory
The participants' responses were used to inform the creation of patient-facing educational resources on CKD and anemia

Patient-Oriented Approach

Three patient partners helped to lead this project. Each patient partner had lived experience with CKD and anemia. The patient partners led the participant recruitment and facilitated the focus groups. They were also consulted throughout the planning, data analysis, and toolkit development stages of the project. Their involvement allowed the research team to ensure that the focus groups and toolkit were beneficial, appropriate and accessible for patients and their caregivers.

Example Focus Group Questions

Has your health care team provided you with the information needed to understand and manage your anemia? If yes, please explain. If not, what information is needed?
Please describe any decision-making challenges you have faced regarding your anemia. What was the decision and why was it difficult? Example: decisions relating to healthcare, medication, diet, or lifestyle.

Results



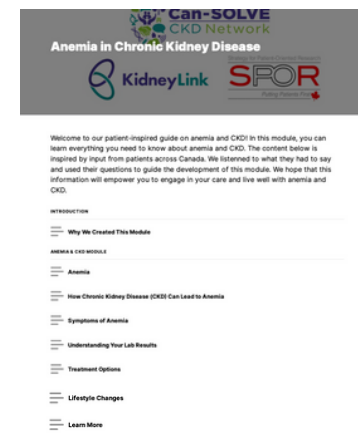
Output #1: Educational Resources

In our focus groups, patients and caregivers discussed their gaps in knowledge and the information they would like to receive on anemia and CKD. Based on their input, we developed an online module, a one-page pamphlet, and a brochure.

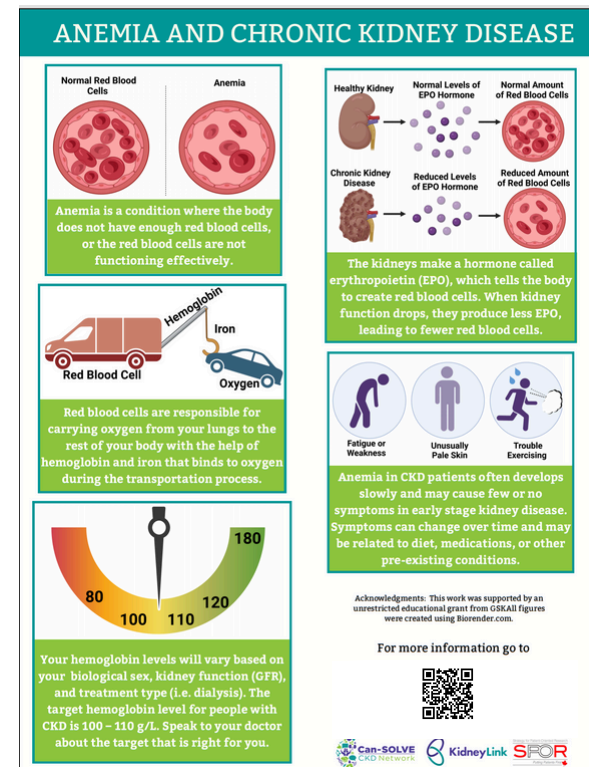
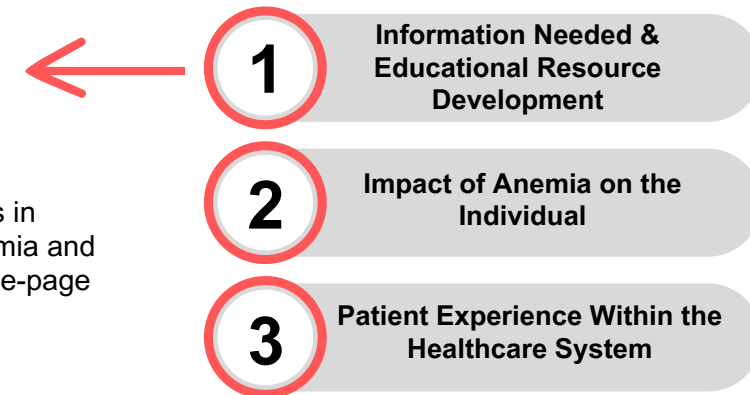
The resources cover the following topics:

- The basics of anemia: what it is and what the symptoms are
- Treatment options
- How to understand your bloodwork values
- Lifestyle: exercise and diet tips
- Learning more: what to ask your care team and where to go for more information

The PDF version of the online module can be accessed using the QR code below.



Screenshot of the homepage for the online module



One-page pamphlet on CKD and anemia. This is a brief summary of the content included in the online module.



Output #1: Research Paper on Challenges & Healthcare Experiences of People with CKD and Anemia

Initially, our goal was to collect data to inform the development of our educational tool. However, analysis of our data revealed important themes about the experiences and daily challenges of CKD patients living with anemia, for which there was a lack of published qualitative work. To address this gap, we have summarized key findings that relate to the patient experience of people living with CKD and anemia. This work will focus on the impact of anemia on the patient, and their experience navigating the healthcare system as someone with both CKD and anemia.

Impact of Anemia on the Individual

- 1 Physical & Emotional Toll of Anemia
- 2 Challenges with Treatment and Management
- 3 Overall Quality of Life

Patient Experience Within the Healthcare System

- 1 Disconnect Between Patient and Healthcare Provider
- 2 Experiences Interacting with Healthcare Team

Conclusions

Our data revealed common themes relating to patients' educational needs, as well as the challenges they face due to their anemia. We have created an online educational module, a one-page pamphlet, and a brochure to address common gaps in the knowledge that relate to anemia and CKD. The next step is to publish the online resource and disseminate the pamphlets and brochures to clinics across Canada. To honour the lived experience of our patient partners and focus group participants, we will also be publishing an article on the challenges they have faced as they manage their anemia and navigate the healthcare system.

References

1. Grandy S, Palaka E, Guzman N, Dunn A, Wittbrodt ET, Finkelstein FO. Understanding Patient Perspectives of the Impact of Anemia in Chronic Kidney Disease: A United States Patient Survey. *Journal of Patient Experience*. 2022 Apr 7;9:23743735221092629. doi: 10.1177/23743735221092629. PMID: 35425851; PMCID: PMC9003657.

Acknowledgements

This project was completed by the Can-SOLVE CKD Network, which is funded by the CIHR Strategy for Patient-Oriented Research. We would like to thank GSK, which provided an educational grant to fund this project. Thank you to Omosami Enilama for designing the graphics for the pamphlet and module.

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