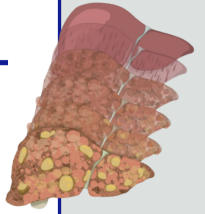


COLLABORATING WITH PATIENTS & CAREGIVERS TO CREATE WEB-BASED EDUCATIONAL RESOURCES FOR PEOPLE AFFECTED BY CIRRHOSIS



AUTHORS

Emily Johnson¹, Ashley Hyde², Derek Drager³, Michelle Carboneau¹, Vincent Bain¹, Jan Kowalcwski⁴ & Puneeta Tandon¹

AFFILIATIONS

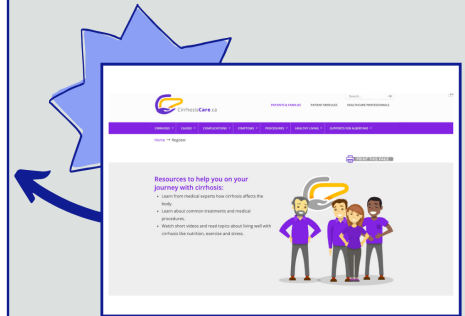
1.Division of Gastroenterology (Liver Unit), Faculty of Medicine & Dentistry, University of Alberta
 2.Faculty of Nursing, University of Alberta
 3.Patient Advisory Team (Cirrhosis Care Alberta)
 4.Neuroscience and Mental Health Institute, University of Alberta

Introduction

- Cirrhosis is a chronic liver disease resulting from vascular and hepatocellular injury
- Patients with cirrhosis can experience complications like hepatic encephalopathy, varices and ascites which have profound impact on their quality of life
- Given the complexity of cirrhosis, patients need high-quality educational resources; however online resources are limited with existing resources characterized by inaccuracy and inaccessibility

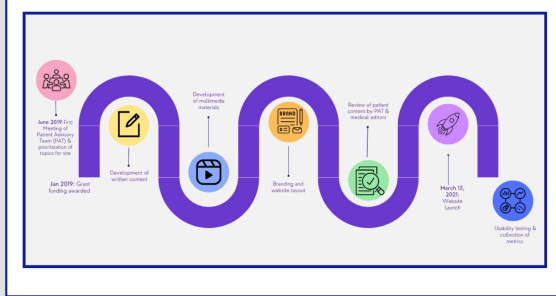
Learnings

- By involving patient partners & caregivers with lived experience of cirrhosis, we created resources that were easy to understand and mindful of the different ways patients like to learn.
- This project demonstrated the importance of fostering collaborative relationships between clinical experts & patient partners to create innovative resources
- It illuminated the complexities of longer-term projects involving multiple groups & the need for a structured communication plan



Objective

- The objective of this project was to design & develop multi-modal online educational resources for patients with cirrhosis and their caregivers, using a patient-oriented approach.

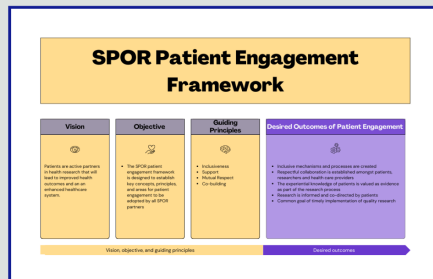


Results

- This 2-year process resulted in a 55-page website and 78 animated & live action videos on cirrhosis
- **Usability testing:** We completed 45-minute usability testing with 10 participants which identified several content, navigation, language & design issues
- **Visitor Feedback:** 92% found the site useful, 94% found the content informative
- **Metrics:** >100,000 unique visitors from across the world; 74.91% located the site via an organic web search

Conceptual Framework

- Using the SPOR framework allowed us to create a shared vision for our educational resources
- Key to our success was our Patient Advisory Team (PAT), comprised of 16 patients & caregivers and clinical experts



Approach

- We followed a stepwise approach:
1. Establishing a shared vision: PAT identified priority topics for cirrhosis education
 2. Developing written materials
 3. Developing video content
 4. Branding
 5. Website design & layout
 6. Improving user accessibility
 7. Website launch & evaluation

