



# The Methods Clusters

In 2016, the BC SUPPORT Unit funded a five-year initiative to study the methods of patient-oriented research: the “**Methods Clusters**”.

We started our work by **listening to stakeholders**—including patients, researchers, policy makers, and practitioners. Together, we identified **6 areas** where more methods research was most important. These became the **6 Clusters**:



*Knowledge  
Translation and  
Implementation  
Science*



*Patient-Centered  
Measurement*



*Data Science and  
Health  
Informatics*



*Patient  
Engagement*



*Health Economics  
and Simulation  
Modelling*



*Real-World  
Clinical Trials*

Each Cluster consulted stakeholders to discuss their **priorities** for patient-oriented research. **35 priorities** surfaced.

To address these priorities, the Clusters funded **42 different projects**. All of these projects were **patient-oriented**: we **studied** patient-oriented research by **doing** patient-oriented research.



This PDF provides a snapshot of the **Patient Engagement** Methods Cluster as of March 2022.



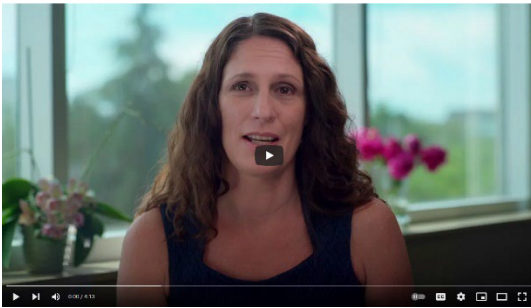
# Patient Engagement

## Overview

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**Patient Engagement** can be understood as meaningful and active collaboration in governance, priority setting, conducting research, and in summarizing, sharing, and putting the knowledge gained into action (i.e., knowledge translation).

It is important to note the term ‘patient,’ as applied here, is overarching and inclusive, referring to people with lived or personal experience of health conditions or issues, the people who support them, such as family members, friends and informal caregivers, and the communities from which they belong.



In [this video](#), **Stirling Bryan** and **Erin Michalak** discuss the Methods Clusters, and how this Cluster identified its key priorities.

Runtime: **4:13**

[Watch on YouTube](#)

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Consulting with researchers, policy makers, and practitioners, this Cluster:

- Identified **4 priorities** to focus on
    - The key priority “advancing and embracing diversity” is shared by all projects
  - Funded **4 projects** to address them
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This Cluster was led by **Erin Michalak**.

**Dr. Michalak’s** background is in psychology, with a PhD awarded from the University of Wales College of Medicine in the UK. Her research expertise lies in patient-engagement in research, Community-Based Participatory Research, knowledge translation, bipolar disorder, quality of life, eHealth/mHealth and implementation science.



# Patient Engagement Navigation

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# Patient Engagement

## Projects: Overview

### **Bridging the digital divide**

*and opening access to online research opportunities in youth and young adults living with mental illness in British Columbia*



**Patient  
 Engagement**



*The objective of this project was to understand and dismantle the barriers to accessing digital information, research, and communication technologies for youth with mental illness in British Columbia.*

### **Diverse Communities Facing Multiple Barriers to Engagement in Patient-Oriented Research**



**Patient  
 Engagement**



*This project focused on understanding meaningful engagement with people with complex medical conditions or who experience housing or food insecurity.*

### **Methods for Supporting Diverse Patient Engagement in a Diverse World: Co-Creation and Evaluation of Interactive Educational Modules**



**Patient  
 Engagement**



*This project developed and tested six video modules to support engagement from diverse people in health research, specifically LGBTQ2S+, d/Deaf, disabled, immigrant, refugee, racialized, ethnocultural, and rural and remote patient partners.*

### **Patient-engaged priority setting and mental health data in the Okanagan Nation**



**Patient  
 Engagement**



*This study utilized syilx Okanagan cultural processes & protocols to engage syilx Okanagan patients in priority setting to inform decision making about health care challenges.*

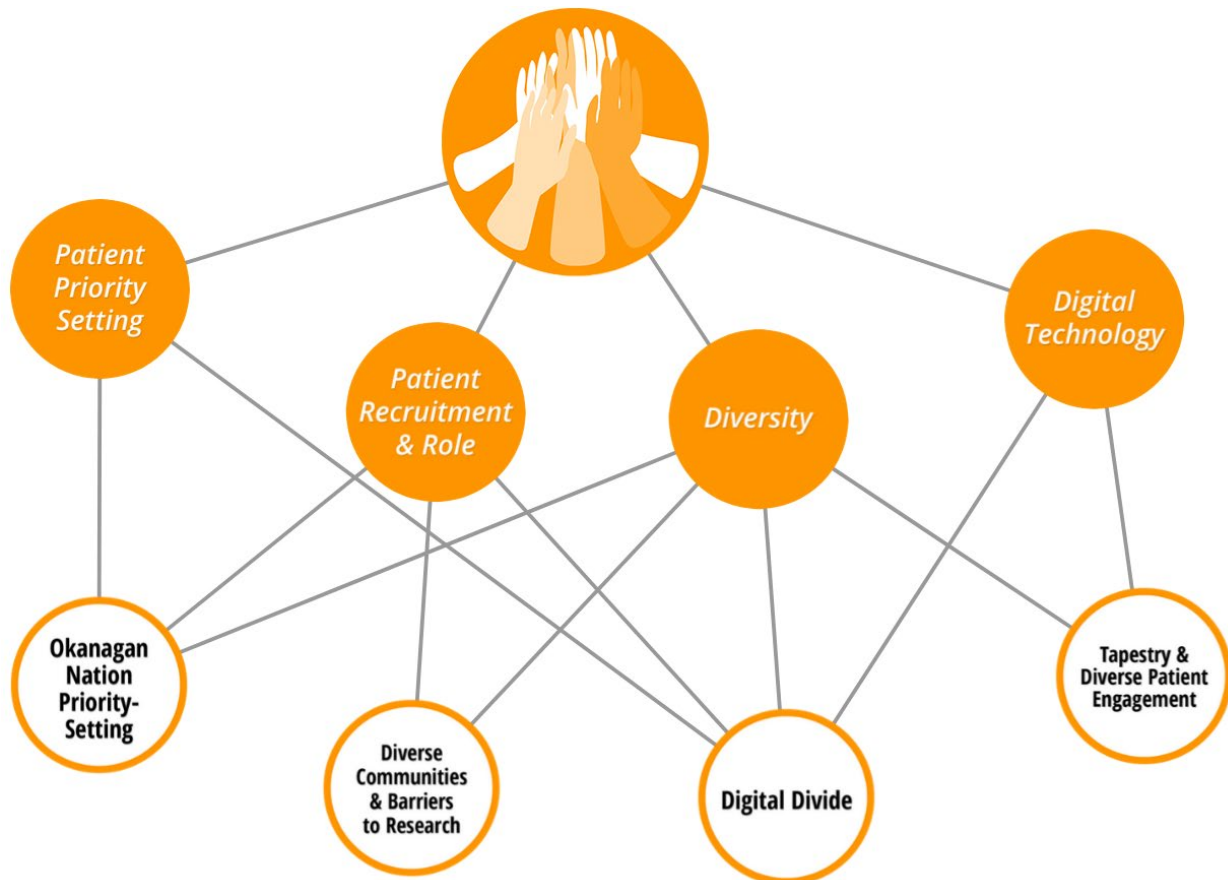


# Patient Engagement

## Priorities

Each Cluster consulted stakeholders to discuss their priorities for patient-oriented research. The Data Science & Health Informatics Methods Cluster identified **4 priorities** for potential projects, with the priority “advancing and embracing diversity” identified as a key priority that should be addressed by all projects.

This Cluster then funded **4 projects** based on these priorities.



*This diagram shows the connections between the priorities (solid orange) and projects (orange outline) of the Patient Engagement Methods Cluster. A list of the Cluster's priorities, and projects they funded based on them, is below.*



## **Advancing and embracing diversity in patient engagement in research in BC**

The projects that addressed this priority were:

- *Bridging the digital divide and opening access to online research opportunities in youth and young adults living with mental illness in British Columbia*
- *Diverse communities facing multiple barriers to engagement in patient-oriented research*
- *Tapestry Tool – Methods for supporting diverse patient engagement in a diverse world: Co-creation and evaluation of interactive educational modules*
- *Patient-engaged priority setting and mental health data in the syilx-Okanagan Nation*

## **Patient priority setting**

The projects that addressed this priority were:

- *Bridging the digital divide and opening access to online research opportunities in youth and young adults living with mental illness in British Columbia*
- *Patient-engaged priority setting and mental health data in the syilx-Okanagan Nation*

## **Advancing methods for, and evaluation of, recruitment and patient role optimisation**

The projects that addressed this priority were:

- *Bridging the digital divide and opening access to online research opportunities in youth and young adults living with mental illness in British Columbia*
- *Diverse communities facing multiple barriers to engagement in patient-oriented research*
- *Patient-engaged priority setting and mental health data in the syilx-Okanagan Nation*

## **Harnessing Digital Health Technologies**

The projects that addressed this priority were:

- *Bridging the digital divide and opening access to online research opportunities in youth and young adults living with mental illness in British Columbia*
- *Tapestry Tool – Methods for supporting diverse patient engagement in a diverse world: Co-creation and evaluation of interactive educational modules*



# Patient Engagement

## Projects

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### **Bridging the digital divide and opening access to online research opportunities in youth and young adults living with mental illness in British Columbia**

Contact: [shelly.ben-david@ubc.ca](mailto:shelly.ben-david@ubc.ca)

This project addressed the priorities:

- *Advancing and embracing diversity in patient engagement in research in BC*
- *Advancing methods for, and evaluation of, recruitment and patient role optimisation*
- *Harnessing digital health technologies*
- *Patient priority setting*

### **Project summary**

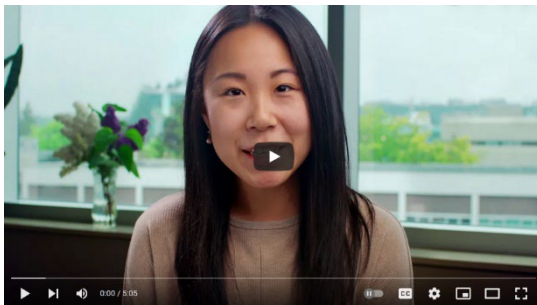
One in four young people in British Columbia experience a mental health issue each year. This project will develop methods to engage youth in health services research and system reform by exploring the digital divide. It has been identified that investments in health care technology may have big potential to help young people with mental illness find and receive care they need.

The objective of this project is to understand and dismantle the barriers to accessing digital information, research, and communication technologies for youth with mental illness in BC.

Our project is in progress. When complete, there will be five main outcomes of this study:



1. A scoping review publication of the digital divide among youth
2. Published qualitative study exploring barriers and facilitators to accessing e-mental health technology among diverse youth in BC
3. A decision-making model for describing the factors of BC youth that influence access and use of digital technologies for health
4. Knowledge translation outputs (tools and strategies) for four stakeholders groups (virtual care providers, Foundry leadership, youth, and families) that help dismantle barriers to accessing digital mental health technology
5. A paper describing the methods for engaging youth with mental illness in research.



[Watch a video](#) summarizing this project, featuring project co-leads **Skye Barbic** and **Shelly Ben-David**, as well as youth ambassadors **Nancy Zhao** and **Alicia Raimundo**.

Runtime: **5:05**

## Project findings

Forty-five youth have participated in a 1-2 hour virtual open-ended interview conducted by youth research assistants. Our interview protocol was based on a decision-making framework called the Unified Theory of Behavior.

We also asked questions related to how their identity (e.g. gender, race, ability, student status, socio-economic status) influenced their help-seeking, and how their use has changed since the pandemic. Thematic analysis was used to report patterns within the data.

### Demographics

- Age: Our youth were between the ages of 12-24 with a mean age of 19.
- Gender: 31% Female, 33% Male, and 38% Two-spirit and Non-Binary. Thirty-eight percent of the youth were Transgender.





- Race: 42% White, 18% Chinese, 13% Mixed ethnicity, 11% Indigenous, 2% Filipino, and 2% South Asian.

## **Discussion topics**

Youth reported their beliefs about:

- Services (e.g., advantages and disadvantages)
- Who approves and/or disapproves of them seeking services
- Strategies and skills they use to access digital services
- Emotions that get in the way and support them accessing services

## **Patterns in the data**

Prior to the pandemic, youth reported not really accessing digital mental health services, but this greatly increased during the pandemic, and will continue to be used in the future.

Youth reported that identity experiences (e.g. gender, race, access to technology, education) do influence access to digital mental health services.

The findings from this study will help shape the development of tools and strategies, and help inform digital mental health services such as Foundry to increase accessibility for all youth in BC.

## **Presentations**

We have conducted four deliberative dialogues with four stakeholders (youth, parents, virtual care providers, Foundry directors). Deliberative dialogues are a knowledge mobilization strategy, where you synthesize your data and present to important stakeholders in the field who can help shape the direction of the findings and outputs.



## Blogs

**June 13, 2019** – Shelly Ben-David & Erin Michalak: [“Bridging the Digital Divide Among Youth in BC”](#) *CREST.BD*

**March 27, 2020** – Dr. Skye Barbic: [“Bridging the Digital Divide of Scoping Reviews in Health”](#) *CREST.BD*

**November 23, 2020** – Julia Gray: [“Behind the Scenes of a Youth Research Assistant”](#) *CREST.BD*

**March 22, 2022** – Naomi Laurin: [“The Digital Divide Study: My First Experience Working on Qualitative Research”](#) *CREST.BD*

## Team

[Shelly Ben-David, Co-lead](#) [✉](#); Skye Barbic, Co-lead; Sara Kolomejac; Melissa Campos; Corinne Tallon; Chantel Breau; Naomi Laurin; Mikaela Basile; Theresa Schwab; Julia Gray; Gurvaan Mann; Alicia Raimundo; Nancy Zhao; Rory Higgs



## Diverse communities facing multiple barriers to engagement in patient-oriented research

This project addressed the priorities:

- *Advancing and embracing diversity in patient engagement in research in BC*
- *Advancing methods for, and evaluation of, recruitment and patient role optimisation*

### Project summary

As patient-oriented research evolves, it is important that we gain more understanding of the best ways to involve a diverse range of patients and community members, particularly those who may face multiple barriers to being part of research teams and projects, such as people living with complex medical conditions or who experience housing or food insecurity.

Our project explored factors that support engagement and partnership in patient-oriented research. We learned about the importance of **building relationships and trust**, and how different approaches may benefit or potential harm those involved.

Our team was co-led with patient and community partners, which we believe was critical to the success of this project.



[Watch a video](#) summarizing this project, featuring project co-leads **Barbara** and **Davina**. This video was created early in the research process.

Runtime: **3:00**



## Project findings

We are working through four main objectives:

### 1. Literature review

*Reviewing the literature to understand what knowledge exists about patient-oriented research for patients and communities facing difficulties in participating.*

With assistance from a UBC librarian, after screening, we have identified a sample of 180 documents. We are in the process of finalizing the key themes of best practices.

### 2. Interviews

*Interviewing researchers and patient or community participants who live in different places in BC, come from different backgrounds and communities, and who have different kinds of experiences being part of research teams.*

We have conducted 35 interviews. Analysis is almost complete, and we will be working with our patient and community partners in January 2022 to interpret findings.

### 3. Synthesis

*Synthesizing this knowledge (bringing this information together) to determine effective methods.*

To be developed in collaboration with patient and community partners.

### 4. Developing Tools

*Developing tools that can support researchers and diverse communities in patient-oriented research and patient engagement activities.*

To be developed in collaboration with patient and community partners.



## **Team**

Dr. Davina Banner, Co-lead; Barbara Croome, Co-lead; Dr. Sue Mills, Co-lead; Dr. Nancy Clark; Daisy Au; Russ Maynard; Ursula Ellis; Shayna Dolan; Maryam Dehnadi; Daman Kandola; Kiran Ghag; Joyce Griffith; Andreea Brabete; Dr. Harneet Gill; Jennifer Brown



# Tapestry Tool – Methods for supporting diverse patient engagement in a diverse world: Co-creation and evaluation of interactive educational modules

Contact: [erin.michalak@ubc.ca](mailto:erin.michalak@ubc.ca)

This project addressed the priorities:

- *Advancing and embracing diversity in patient engagement in research in BC*
- *Harnessing digital health technologies*

## Project summary

The BC SUPPORT Unit Patient Engagement Methods Cluster undertook an extensive consultation involving diverse stakeholders to identify compelling patient engagement (PE) research to support across our province. A prominent theme of that consultation was that PE in research **must embrace diversity**. The consultation found that, among patient partners engaged in research, certain populations were routinely underrepresented. Knowing how to identify and address the barriers that these populations face in accessing research opportunities may help research teams increase diversity and equity among the patient partners that they engage.

Furthermore, online platforms can be a convenient, cost-effective and enjoyable way to learn about health research; however, not a lot of content is co-created by researchers and patients, which is a missed opportunity to potentially improve the quality of content and promote research engagement.

Five teams, each including at least one patient partner as well as an academic researcher, were formed to create video-based educational modules to help research teams engage these underrepresented populations:

1. LGBTQ2S+ communities



2. Rural and remote communities
3. d/Deaf communities
4. Disabled communities
5. Immigrant, refugee, ethnocultural, and racialized communities

The patient partners—and, often, the academic researchers—had lived experience as members of at least one of these underrepresented communities.

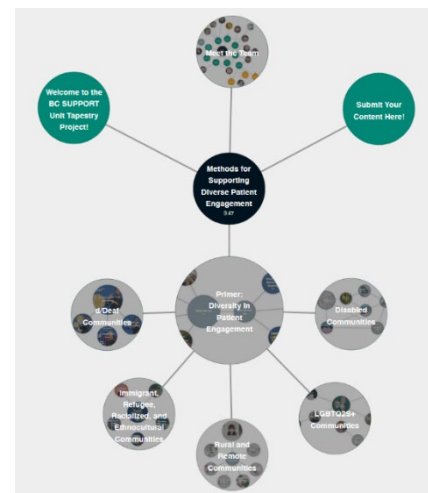
A sixth team developed a module that would serve as a primer to the topic of diversity and equity in PE in research.

Teams performed environmental scans, then wrote scripts and developed storyboards. These videos are hosted on the Tapestry platform, which presents them in thematically linked webs. Once fully evaluated in 2022, they will be released to the public.

The videos offer a launching-off point to discuss diversity in PE from the perspectives of underrepresented communities. They explore the barriers to PE and some ways to overcome them, while issuing a call to action to research teams to more actively advocate for participatory equity at a systemic level. These educational modules acknowledge that they reflect some underrepresented perspectives but not all, but the Tapestry platform offers a flexible way to invite community co-creation of new resources for each module or new modules to continue the conversation into the future.

## Tapestry modules

[Access the modules here.](#)





## Module “teaser” videos



[Watch the “Primer” teaser video](#)



[Watch the “Disabled” teaser video](#)



[Watch the “Rural and Remote” teaser video](#)



[Watch the “LGBTQ2S+” teaser video](#)



[Watch the “d/Deaf” teaser video](#)



[Watch the “Immigrant, Refugee, Racialized & Ethnocultural” teaser video](#)





## Blogs



**September 29, 2021** - Bev Pomeroy & Linnea Ritland: [“Beyond pronouns and rainbow logos: How do you know you’re ready to engage with LGBTQ2S+ folks?”](#) *Health Research BC*



**September 16, 2021** – Erin Michalak: [“How do we do diverse patient engagement—better?”](#) *Health Research BC*

**August 27, 2021** – BC SUPPORT Unit: [“Call for health researchers: Help increase diversity in health research in BC!”](#) *CREST.BD*

**June 25, 2020** – Dr. Iva Cheung: [“Diversity in Patient Engagement: Meet the Tapestry teams”](#) *CREST.BD*

**November 7, 2019** – Dr. Iva Cheung: [“Diversity in patient engagement: A call for patient partner and academic researcher leads”](#) *CREST.BD*

**October 17, 2019** – Dr. Iva Cheung: [“BC SUPPORT Unit: Educational Tools to Support Diverse Research”](#) *CREST.BD*

## Presentations

**Oct 2021:** Disability Politics 101 workshop, Hollyhock, virtual via Cortes Island, BC

**Mar 2021:** Simon Fraser University Faculty of Health Sciences research seminar “Co-creating research communications with patients”




**Feb 2021:** Public/Patient Engagement Community of Practice quarterly meeting:  
“The Tapestry Project: Tools to support equity and diversity in patient engagement  
in research”

**Jan 2021:** Invited presentation at the Health Care Systems Research Network  
(HCSRN) PER SIG Webinar

**Oct 2020:** BC SUPPORT Unit Putting Patients First Conference 2020, Connecting  
Face to Face in Virtual Space – Oral Presentations: Patient Engagement

## Team

[Dr. Erin Michalak, Co-lead](#) ; Dr. Steven Barnes, Co-lead; Dr. Rachelle Hole, Co-I; Dr. Iva Cheung, Co-I; Linnea Ritland; Bitu Jokar; Melanie Butt; Caden Poh; Lin Chen; Anita David; Vidhi Thakkar; Hannah Burton; Mari Klassen; Robin Metcalfe; Gabrielle Peters; Rachelle Hole; Beverley Pomeroy; Travis Salway; Michelle Walker; Ryan Tine; Charlene Burmeister; Shawna Bennett; Theresa-Maria Fournier; Amanda Slaunwhite; Allyshia Van Tol



# Patient-engaged priority setting and mental health data in the syilx-Okanagan Nation

This project addressed the priorities:

- *Advancing and embracing diversity in patient engagement in research in BC*
- *Advancing methods for, and evaluation of, recruitment and patient role optimisation, patient priority setting*

## Project summary

The Okanagan Nation Alliance (ONA) is a Tribal Council supporting syilx Okanagan communities. ONA has identified mental health as a priority area. While the political and social landscape has been slowly shifting to incorporate culturally relevant and appropriate services, challenges remain because the current western system does not understand and support syilx Okanagan world view of wellness and health.

This study is framed by engagement with syilx Okanagan Nation members and seeks to leverage Indigenous syilx knowledge and approaches to ensure access to meaningful and culturally safe health care for nation members.

*captikwł (oral stories)* provide instruction on syilx Okanagan natural laws and protocols that need to be followed in order to live in harmony with all creation including oneself. This study reflects discussions nation members had about priorities related to syilx health from engaging with *captikwł* teachings about syilx Okanagan wellness. Syilx Okanagan participants incorporate lived experiences, including those with mental health, in community decision making about mental health priorities.

The central output will be a greater understanding the significance of local context in Indigenous mental health and patient engagement (PE).



## Project findings

This project has been wonderful for forging strong university-Indigenous (UBC-ONA) relations, and for reaffirming the importance of local Indigenous health knowledge for shaping solutions to Indigenous health.

So far, we have successfully implemented the project to date, using syilx Okanagan knowledge and protocols, including Okanagan approaches to wellbeing, captikwł story work, and traditional stories.

ONA, and by extension the community more broadly, have extended their capacity for research, through the training experiences of ONA staff and of two syilx students' involvement in the project.

At this stage, we are collecting and analyzing data.

We anticipate producing a resource to be used by ONA and the Okanagan communities at large, as well as a publication and conference presentations. These outputs are subject to ongoing revision by our community partners based upon community needs.

## Team

Jennifer Lewis; Raila Dallevoert; Branden Te Hiwi; Jeannette Armstrong; Mike Evans; Kalli Van Stone