

# Eugene Washington PCORI Engagement Award: DISRUPTS

**Celebrating the end of the project!**

## **ONLINE SESSIONS EDUCATE THE COMMUNITY ON COVID-19 AND PATIENT-CENTERED HEALTH ISSUES**

**Hundreds of participants received critical information**

The PATIENTS Program at the University of Maryland School of Pharmacy, working with the St. Lawrence Health (SLH) Clinical and Rural Health Research Department, finished a successful project to give information to New York's North Country region about issues surrounding COVID-19 and the importance of patient-centered research.

As part of the project, titled Developing InfraStructure for Research to Utilize Patient-centered Techniques (DISRUPTS), the PATIENTS Program worked with St. Lawrence Health providers, clinical staff, patients, and community members on how to successfully work with the community in patient-centered outcomes research (PCOR). Webinars were co-developed to shape patient-centered research in this rural area of Northern New York.

Patient-centered outcomes research means that researchers work with

patients and stakeholders to identify and address questions and outcome measures of importance to patients and the community, making sure to include the patient voice when research questions are developed, in research design, implementation, and results sharing.

In Fall 2020, the DISRUPTS project got more funding to create webinars that expanded the community's understanding of PCOR in the context of the COVID-19 pandemic. The webinars, hosted on St. Lawrence Health Clinical and Rural Health Research Department's website at <https://www.stlawrencehealthsystem.org/services/clinical-research>, were informed by different points of view. Experts from the community explained current safety measures, vaccine facts, and more.

**“Input from our Stakeholder Advisory Committee, which consisted of patients, people who have taken part in research, community members, and clinical and non-clinical health care workers, drove the content of these webinars,” said Carly Lovelett, MS, MBA, CCRP, director of clinical research with St. Lawrence Health System.**

“The patient-centered outcomes research webinars had a 112% attendance rate, meaning more people attended the sessions than had registered. The DISRUPTS team was proud to give information about how the North Country can take part in research as well as critical information about COVID-19, allowing the North Country community to take charge of their health. We were happy to learn that the webinars were well-received, with attendees showing high satisfaction on a series of feedback questions,” added Lovelett.

“By working with St. Lawrence Health to help create a patient-centered research infrastructure, our focus was to improve the health of the North Country in rural upstate New York,” said Michelle Medeiros, MS, MA,

CCRP, director of research with the PATIENTS Program. “We involved the community in creating webinars to give critical information about COVID-19 and getting involved in research. We at the PATIENTS Program were proud to work with the community on the project.”

The project developed a series of webinars about patient-centered research, as listed below (links to the recordings included):

### **Learning Together, Leading Together: Shaping Patient-Centered Research in the North Country:**

**Part 1:** [Introduction To and Examples Of Patient-Centered Outcomes Research](#)

**Part 2:** [Research Methods and Engagement Principles](#)

**Part 3:** [Key Considerations for Engaged Research and the Importance of PCOR and Community Involvement](#)

The COVID-19 public information webinars are listed below:

#### **Topic: *Vax Versus Fiction: Answering Questions and Presenting the Facts about COVID-19 Vaccines***

Discussion included comparing the Pfizer and Moderna vaccines, vaccination safety, phased approach to vaccine distribution, herd immunity, and how to get ready to get the vaccine and what to expect. Presented by Kylie Broughal, PA-C. [Watch a recording of the webinar](#)

#### **Topic: *COVID-19: Fact Versus Fiction***

Discussion included COVID-19 compared to the flu, how well masks and social distancing work, and COVID-19 testing. Presented by Kylie Broughal, PA-C. [Watch a recording of the webinar](#).

#### **Topic: *COVID-19 in Rural America***

Discussion included how COVID-19 can be treated, and how the pandemic is different here than in urban America. Presented by Eyal Kedar, MD. [Watch a recording of the webinar](#).

Topic: **COVID-19 and Mental Health/Substance Use** (not aired live; distributed as recorded videos):

- [The Impact of COVID-19 on Substance Use](#), presented by: Emily Marquart, LMHC, CASAC; Emma Brackett, LCSW, CASAC; and Elizabeth Stiles, LPN
- [Navigating COVID-19 and the Impact on Children and Families](#), presented by: Heather Rich, LCSW, CASAC; and Laurie Zweifel, PhD
- [COVID-19 and School](#), presented by: Andrea Randall, Canton Central School Social Worker
- [COVID-19 and Mental Health](#), presented by Tyree Smith
- [St. Lawrence County COVID-19 Response: A Year in Review](#), presented by: Dana McGuire

**“Patient-centered research is important to the health and wellness of our community,” explained Jolene Carotenuto, RN, a nurse educator with SLH and an attendee of the PCOR series.**

“By focusing on the unique needs of our rural population, patient-centered research brings local health care needs to the national stage and brings national research efforts to our small community,” added Carotenuto.

Future plans for the DISRUPTS team include continuing a patient-centered research focus group in an effort to make sure SLH research incorporates the patient voice and investigates topics important to North Country residents. This two-year initiative was partially funded through a Eugene Washington Engagement Award from the Patient-Centered Outcomes Research Institute (PCORI), which is a non-profit organization that funds studies that can help patients and those who care for them make better-informed healthcare choices. The statements presented in this article are solely the responsibility of the author(s) and do not necessarily represent the views of the Patient-Centered Outcomes Research Institute® (PCORI®), its Board of Governors or Methodology Committee.

# ST LAWRENCE HEALTH

An Affiliate of Rochester Regional Health

## DISRUPTS

Developing InfraStructure for Research to Utilize Patient-centered Techniques

### Project Start Date September 1, 2019



The Clinical and Rural Health Research Department launched DISRUPTS (Developing InfraStructure for Research to Utilize Patient-centered Techniques at SLHS)

### Formation of Committee

Sept - Dec 2019



Identified and engaged patients, past research participants, community members, and clinical and non-clinical professionals to form a Stakeholder Advisory Committee

### Co-Developed Series

Feb - Sept 2020

Co-developed "Learning Together, Leading Together," a **three-part educational series** on patient-centered research based on community input and interests



**190**  
Responses



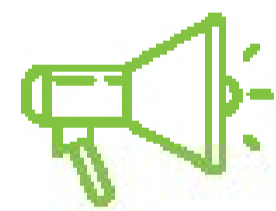
### Surveyed Community

Jan - Feb 2020

Surveyed the community about knowledge and interest in learning about Patient-Centered Outcomes Research

### Community Outreach

Sept 2020 - Jan 2021



Community outreach and advertisement of learning opportunities

### Webinars

Oct 2020 - Jan 2021

To watch these sessions, check out the **St. Lawrence Health Clinical Research** web page

**118**  
Attendees



Scan Me!



### Research Focus Group

Dec 2020 - May 2021



Identified and engaged potential members for a patient-centered research focus group, to provide input on future SLH research

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## COVID-19 Enhancement

DISRUPTS (Developing InfraStructure for Research to Utilize Patient-centered Techniques)

### Awarded Funding

July 28, 2020

Awarded PCORI COVID-19 Enhancement



START

### Project Start

September 2020

### Formation of Committee

November 2020

Formed COVID-19 committee, consisting of COVID-19 survivors, healthcare professionals who treated patients with COVID-19, community members, and patients



### Surveyed Community

Nov 2020 - Feb 2021

Surveyed the community about COVID-19 knowledge, behaviors, interests, and questions

TAKE SURVEY

### Co-Developed Sessions

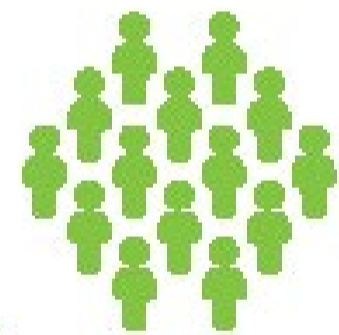
Oct 2020 - Jan 2021

- COVID-19: Fact Versus Fiction
- COVID-19 in Rural America
- COVID-19 and Mental Health/Substance Abuse Series (pre-recorded)



340

Total Attendees



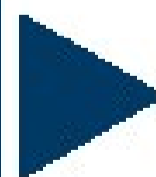
More than

660

views of the recordings



- **Vax Versus Fiction**; Answering Questions and Presenting the Facts about COVID-19 Vaccines



28%

More likely to get the COVID-19 vaccine after attending the "Vax Versus Fiction" vaccine webinar