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 **Data Science and Health Informatics** Methods Cluster as of March 2022.

Data Science & Health Informatics

Overview

Data Science is an umbrella term for techniques used when trying to uncover insights and information from data. It is the intersection of statistics, mathematics, computer design, and programming.

Health Informatics is the use of information and communication technologies in health care. It is also known as *eHealth*, *digital health,* or *biomedical informatics.* It is the intersection of computer, library, cognitive, organizational, and health sciences.

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

- *Identified **5 priorities** to focus on*
- *Funded **3 projects** to address them*

This Cluster was led by **Kim McGrail** and **Leanne Currie**.

Dr. McGrail is a Professor at UBC in the School of Population and Public Health and the Centre for Health Services and Policy Research, Scientific Director of Population Data BC, and the PI for the SPOR Canadian Data Platform. Her research interests are quantitative policy evaluation, aging and the use and cost of health care services, learning health systems and all aspects of population data science. She conducts research in partnership with clinicians, policy-makers and the public. Kim is a founding member of the International Population Data Linkage Network and founding Deputy Editor of the International Journal of Population Data Science.

Dr. Currie conducts research in the field of nursing, biomedical, and health informatics. Her current projects are related to use of technology in the homecare setting including wound diagnosis and management. Her methods include using a sociotechnical approach to system development including user interface design, workflow analysis and use of data science/AI methods.

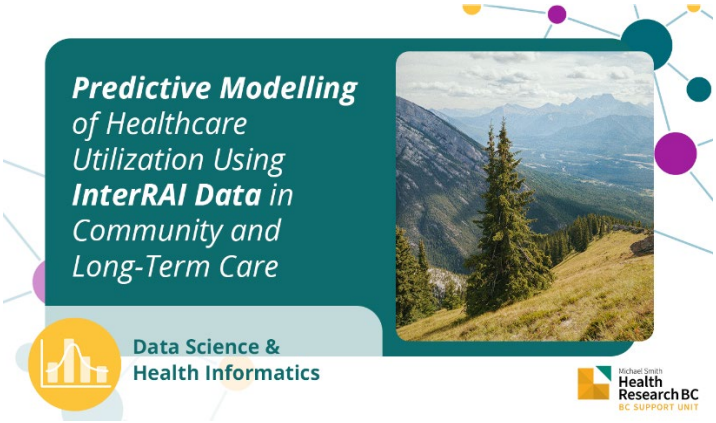
Data Science & Health Informatics

Navigation

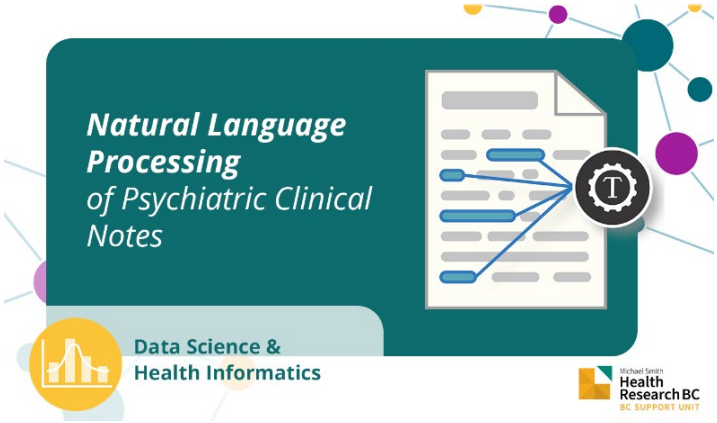
Jump to:

Data Science & Health Informatics

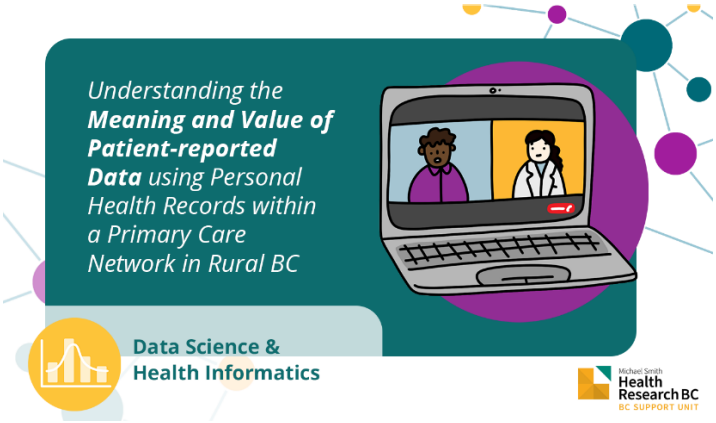
Projects: Overview



This project tried to predict how people will use the health care system in Northern and Interior BC, using advanced data science methods and interRAI data.



Personal health records (PHR) are not yet widely used, and our understanding of their potential, their problems, and how to get the most value from them is limited. This project sought to find out more.



Clinical notes contain valuable data. But, they are difficult to use in large-scale analyses. Could text mining software help with this, and help predict suicidality?

Data Science & Health Informatics

Priorities

Each Cluster consulted stakeholders to discuss their priorities for patient-oriented research. The Data Science & Health Informatics Methods Cluster identified **5 priorities and 14 sub-themes/areas** for potential projects.

This Cluster then funded **3 projects** based on these priorities.

This diagram shows the connections between the priorities (solid yellow) and projects (yellow outline) of the Data Science & Health Informatics Methods Cluster. A list of the Cluster's priorities, and projects they funded based on them, is below.

Data ecosystems with integration of person-centred data
Sub-themes:

- *Data infrastructure to support care coordination and health information exchange.*
- *Data sets that would advance natural language processing (NLP) and other text-based analytics in healthcare (e.g. patient reported experience measures (PREMs))*
- *Information architecture modeling for community data*
- *Robust architecture to support advanced data science analytics such as machine learning.*
- *Database visualization methodologies for healthcare*

The project that addressed this priority was:

- *Natural language processing of psychiatric clinical notes*

Application of specific types of data science methods to support patient-centred healthcare
Sub-themes:

- *Visual Analytics, NLP, machine learning, etc.*

This project that addressed this priority was:

- *Natural language processing of psychiatric clinical notes*

Analytic approaches to address big data & the internet of things in the health context
Sub-themes:

- *Home monitoring*
- *Systems for chronic disease virtual care*

The projects that addressed this priority were:

- *Natural language processing of psychiatric clinical notes*
- *Understanding the meaning and value of patient-reported data using personal health records within a primary care network in rural BC*

Integrated technology and analytic infrastructure that informs patient care
Sub-themes:

- *Analytics that inform point of care clinical decision support systems.*
- *Predictive models across disparate electronic medical/health records (EMRs/EHRs)*

The projects that addressed this priority were:

- *Natural language processing of psychiatric clinical notes*
- *Predictive modelling of healthcare utilization using interRAI data in community and long-term care*

Opportunities to transform healthcare data by focusing on patient-centredness

Sub-themes:

- *Personal health records (PHRs)*
- *Personalization and tailoring*
- *Data mining to identify unique patient and/or clinical subgroups*
- *Integration of health and non-health data (e.g. social media data)*

The projects that addressed this priority were:

- *Understanding the meaning and value of patient-reported data using personal health records within a primary care network in rural BC*
- *Predictive modelling of healthcare utilization using interRAI data in community and long-term care*

Data Science & Health Informatics

Projects

Predictive modelling of healthcare utilization using interRAI data in community and long-term care

Contact: pjackson@tru.ca

This project addressed the priorities:

- *Integrated technology and analytic infrastructure that informs patient care*
- *Opportunities to transform healthcare data by focusing on patient-centredness*

Project summary

In our project, "Predictive Modelling of Healthcare Utilization" (POPMHU), we tried to predict how people will use the health care system in Northern and Interior British Columbia.

To do this, we used:

- advanced data science methods, specifically:
  - machine learning
  - computational modelling
  - visual analytics
- interRAI data
  - InterRAI tools are assessments used to record clients' experiences and health care needs. They are used across Canada and in dozens of countries worldwide.
  - Specifically, interRAI assessments focus on people with chronic illness or disabilities.
  - There are also tools for multiple health care sectors. For example, interRAI tools could be used to assess a client's use of mental health services and personal assistance services.

- Often, patients assessed using interRAI are older people. Older people's experiences, and the experiences of people who support them, are a central focus of our project.

Project findings

We wanted to:

- Predict clients' movement across the continuum of care (e.g., from community care to long-term care or vice versa).
- Identify how we can use new computer tools (e.g., machine learning, integrative modelling) with existing healthcare systems, priorities, and processes. We are also exploring the best ways to engage patient partners in machine learning research.
- Develop capacity for machine learning work in Northern and Interior BC. To assist in team collaboration, we created a POPHMU project wiki.

Together with patient partners, researchers, trainees, decision-makers, and health systems experts, we collaborated to use machine learning analysis techniques in new ways to answer questions of interest. We developed new communication methods, approached our research activities in new and unique ways, and created visual ways to communicate our findings in ways that are user-friendly.

Presentations

December 2021: Northern Health Research Conference

October 2021: IFIC (International Foundation for Integrated Care) NACIC2021 – 1st North American Conference on Integrated Care, Toronto, Canada

October 2021: CAG (Canadian Association on Gerontology) 2021 conference

October 2021: IEEE 12th Annual Information Technology, Electronics and Mobile Communication Conference (IEMCON)

October 2020: 2020 BC SUPPORT Unit's Putting Patients First conference

Team

Dr. Shannon Freeman, co-PI, Dr. Piper Jackson, co-PI ✉, Dr. Waqar Haque, co-I Brent Baker, Grace Kramer, Susan Prior, Carl Zanon, David Watts, Alanna Koopmans, Lila Mansour, Alexander Kitsul, Isayha Raposo, Jordan Ho, Gavin Howard, Giridhar Krishnan, Navjot Kaur, Michael Fayemiwo, Robin Teotia

Understanding the meaning and value of patient-reported data using personal health records within a primary care network in rural BC

This project addressed the priorities:

- *Analytic approaches to address big data & the internet of things in the health context*
- *Opportunities to transform healthcare data by focusing on patient-centredness*

Project summary

Personal Health Records (PHR) are computer-based tools in which patients can keep a record of information about their health. This information or patient-reported data includes medications, blood pressure readings, exercise activities, and family health history. Some PHRs allow a patient to connect to their primary care provider, usually a doctor or nurse practitioner. This allows patients to manage appointments, view test results, and even communicate with their provider via videoconference, texting, or email.

The COVID-19 pandemic has made the use of these remote, or virtual, options for receiving care even more important. However, PHRs are not yet widely used and our understanding of their potential, their problems and how to get the most value from them is limited.

To explore these questions, we conducted a two-phase study:

1. In phase 1, we held **focus groups** to understand what PHRs mean to patients and providers, and what features of a PHR system would be most useful.
2. In phase 2, we asked patients and their health care providers to **use a PHR system,** so that we could explore the value of the patient-reported data shared in this way.

Project findings

Patients and providers had some similar but different ideas about the PHR:

- They both thought it should be centered on the patient
    - But, they thought differently about the types of information it should include and who should control it
- Patients thought they should control the PHR, and even though providers didn't disagree, they admitted that the way things are set up currently leaves providers in charge of it

The PHR used in this study was supposed to let patients and providers add and share information, but because it wasn't connected to the provider's system for keeping patient information, and COVID-19 occurred at the same time, it didn't happen easily.

But, a few patients used it, and even though it didn't change their quality of life or their confidence in managing their chronic diseases, "keeping things the same" might be seen as a good thing—considering the pandemic might have made things worse.

One "shining example" we observed was a clinic that had everything in place so that patients and providers could communicate through a portal with secure email, messaging, video, online appointments, and a library of forms for patients to report on different aspects of their health.

It represents a true partnership between patients and providers, where patients felt safe and cared for 24/7, and both patients and providers were highly satisfied.

Project infographics on next two pages.

THE UNIVERSITY OF BRITISH COLUMBIA

Understanding the Meaning & Value of Patient-Reported Data
Using Personal Health Records Within a Primary Care Network in Rural BC

Prioritising Patient-Centered Research Approaches

Key Factors For Success From Our Project Journey

Valued & Equal Perspectives

Valuing patient-partners in presenting a patient lens & as key members of the research team

Meaningful Engagement

Maintaining a spectrum of patient engagement throughout the project

Relationship & Connection

Meeting regularly throughout the project built relationship & resilience

Rural BC Virtual Care & Patient-Centered Research Matters!

Michael Smith Health Research BC
BC SUPPORT UNIT

Interior Health

Kootenay Boundary Division of Family Practice
A GPSC initiative

THE UNIVERSITY OF BRITISH COLUMBIA

Understanding the Meaning & Value of Patient-Reported Data
Using Personal Health Records Within a Primary Care Network in Rural BC

System-Level Changes

To Support Patient-Centered Virtual Care In Rural BC

Accessibility
Inclusion of Plain Language Patient Health Information Within Digital Tools

Infrastructure
High-Speed Internet Access for Rural & Remote Areas

Training
Physician & Patient Training for Use of Digital Health Tools

Funding
Stable Funding & Low-Cost Digital Tools

Team Workflows
Use of Patient Feedback to Inform Optimal Health Care Team Workflows & Responsibilities

Rural BC Virtual Care & Patient-Centered Research Matters!

Michael Smith Health Research BC
BC SUPPORT UNIT

Interior Health

Kootenay Boundary Division of Family Practice
A GPSC initiative

Publications

Currie, L.M., Rush, K.L., Burton, L., Mattei, M., Gorges, M. (2021). Perceptions of personal health records in rural primary care clinics in Canada: Patient perspectives. Studies in Health Technology and Informatics, 284, 285-289.

Görges, M., Rush, K.L., Burton, L., Mattei M., Davis S., Scott H., Smith M. A., Currie L. M. (2021). Preferred functions of personal health records in rural primary health clinics in Canada: health care team perspectives. Applied Clinical Informatics, 12(01), 041-048.

Rush, K.L., Burton, L., Singh S., Smith M. A., Schaab K., Görges M., Janke R., Currie L. M. (2021). News article portrayal of virtual care for health care delivery in the first 7 months of the COVID-19 pandemic. Telemedicine Reports, 2.1, 108–117.

Presentations

November 2021: "When a Pandemic Gives You Lemons, You Run With It" *Methods Matters* (BC SUPPORT Unit)

Runtime: 54:51

September 2021: "Lessons from an Attempted PHR Implementation: Rural Primary Care Practices." Patient Advisory Committee Presentation.

October 2021: "Understanding Preventive Care Needs, Self-Efficacy and Opportunities for Unattached Rural Patients in British Columbia." Presented at the Alberta SPOR Unit Virtual Institute.

May 2021: "Patients' Electronic Data-Sharing During the Pandemic." Rapid Fire presentation at Canadian Nurses Informatics Conference.

November 2020: "Personal Health Records within a Primary Care Network in Rural BC: Learnings from Phase 1 Pre-Implementation." Invited presentation to Rural PHR Partnership Committee under oversight of the Rural Coordination Centre and Ministry of Health

October 2020: "PHR – Contrasting Views of Rural Patients and Providers." SPOR's Putting Patients First 2020.

June 2020: "Addressing Rural Inequities in Healthcare." Retired Teachers of Ontario Monthly Seminar Series.

Team

Dr. Kathy Rush, Lead
Dr. Leanne Currie, Dr. Matthias Görges, Dr. Selena Davis, Mindy Smith, Heidi Scott, Mona Mattei, Lindsay Burton

Natural language processing of psychiatric clinical notes

This project addressed the priorities:

- *Analytic approaches to address big data & the internet of things in the health context*
- *Application of specific types of data science methods to support patient centred healthcare*
- *Data ecosystems with integration of person-centred data*
- *Integrated technology and analytic infrastructure that informs patient care*

Project summary

Suicide is the second leading cause of death in youth and despite a growing body of research, mental health concerns in youth are still prevalent and under-treated. Understanding and identifying the risk factors associated with suicide in youth experiencing mental health concerns is paramount to early intervention. Forty-five percent of patients are admitted annually for suicidality at BC Children's Hospital (BCCH).

At admission and discharge, patients receive extensive diagnostic assessments largely recorded as long narrative clinical notes. The reports are difficult to incorporate in large-scale analyses, as manual information extraction is laborious and prone to error.

Natural Language Processing (NLP) methodology is increasingly applied to extract meaningful information from free-text style clinical notes. It transforms the unstructured information embedded in the text into categorical and numerical fields amenable to data analysis.

There have only been limited applications of NLP to the mental health field. Most mental health clinical documentation is done through long narratives, which does not fit well into structured fields.

Our study aimed at investigating if NLP can be used to predict suicidality from clinical notes.

In particular, we explored the utility of sentiment analysis, a branch of NLP used most often to identify and quantify the sentiment, feelings, or opinions associated with a topic.

Project findings

We developed a psychiatry-relevant lexicon and identified specific categories of words, such as thought content and thought process that had significantly different "polarity" (negative or positive sentiment) between suicidal and non-suicidal cases.

In addition, we demonstrated that the individual words and their associated polarity can be used as features in classification models and carry informative content to differentiate between suicidal and non-suicidal cases.

In conclusion, our study reveals that there is much value in applying NLP to psychiatric clinical notes and suicidal prediction.

Publications

George A, Johnson D, Carenini G, Eslami A, Ng R, Portales-Casamar E. Applications of Aspect-based Sentiment Analysis on Psychiatric Clinical Notes to Study Suicide in Youth. AMIA Jt Summits Transl Sci Proc. 2021 May 17;2021:229-237.

Presentations

March 2021: "Applications of Aspect-based Sentiment Analysis on Psychiatric Clinical Notes to Study Suicide in Youth," AMIA Informatics Summit

November 2020: "Applications of Aspect-based Sentiment Analysis on Psychiatric Clinical Notes to Study Suicide in Youth,"; E2i Fall Research Forum

September 2019: "Artificial Intelligence and Machine Learning in Pediatric Mental Health," 39th Annual Canadian Academy of Child and Adolescent Psychiatry Conference

April 2019: "Artificial Intelligence explorations at the Child and Adolescent Psychiatric Emergency (CAPE) Unit," BCCH Artificial Intelligence in Healthcare Workshop

March 2019: "Text Mining Psychiatric Clinical Notes," 2019 UBC Multidisciplinary Undergraduate Research Conference

February 2019: "Natural Language Processing of Psychiatric Clinical Notes," 2019 Information Technology & Communications in Health (ITCH) Conference

November 2018: "Text Mining Psychiatric Clinical Notes," BCCH Evidence to Innovation (E2i) 2018 Research Day

July 2018: "Text Mining Psychiatric Clinical Notes," BCCH Research Education Program Poster Day

Team

Elodie Portales-Casamar, Lead; Ali Eslami, Co-I; Raymond Ng, Co-I; Giuseppe Carenini, Co-I; Ali Mussavi Rizi, Co-I
Ahmed Abura'ed, postdoctoral fellow; Yuqian Zhuang, data scientist; Ariel Qi, patient partner; Alison Taylor, patient partner; Omar Bseiso, patient partner

Alumni:
Rebecca Lin, Esther Lin, Amy George, Cindy Ou Yang