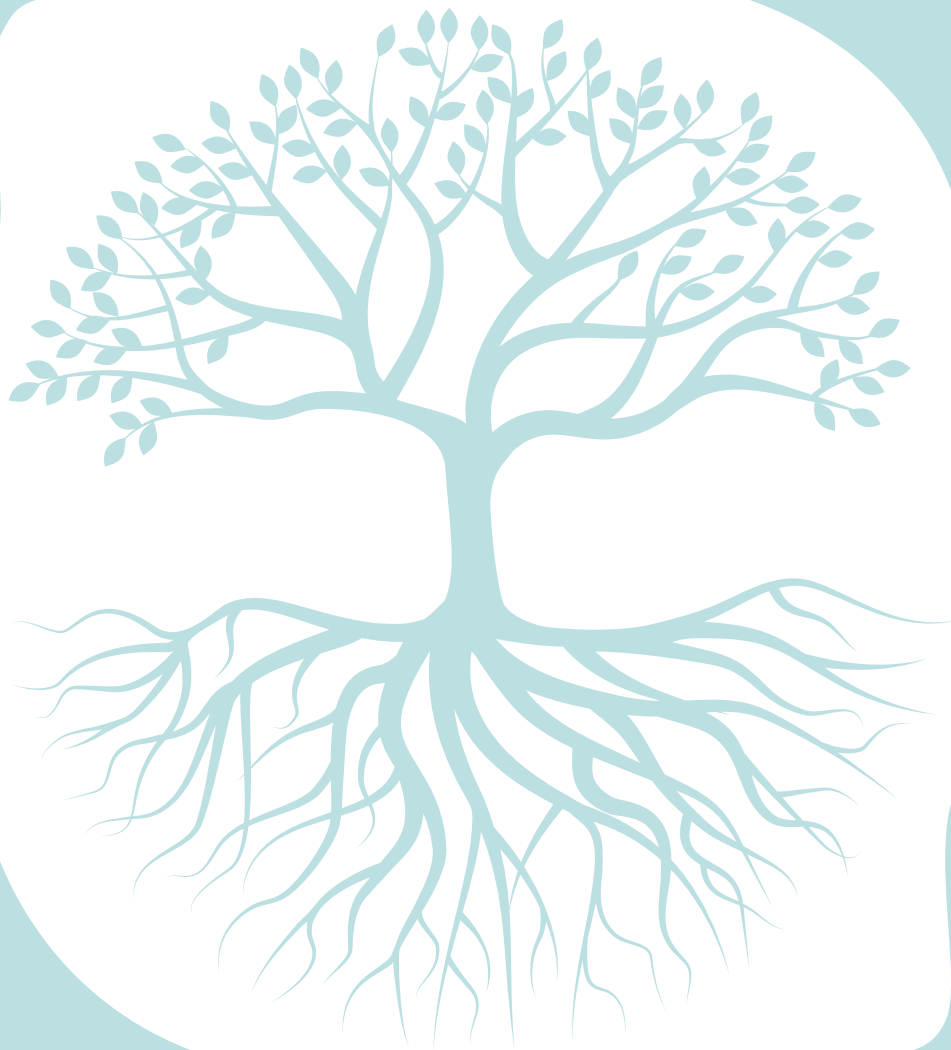


HEARING THE PATIENT VOICE:

Improving health care for
people with complex mental health
disorders in Saskatoon

A REPORT BY:

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and the Hearing the Patient Voice Advisory Group Members



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Advisory group members cross patient, family member, community and health region borders. These individuals came together and worked with a great level of respect and care in the hopes that the quality of care will be improved for individuals living with mental health and/or addictions issues in the Saskatoon Health Region.

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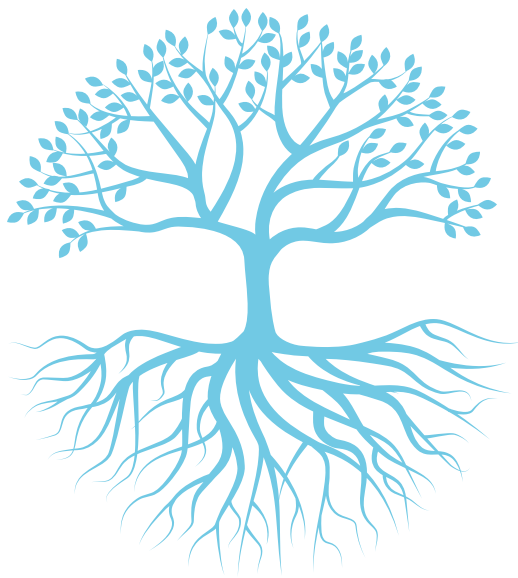
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I. INTRODUCTION

Health care has a long tradition of working *for* patients, rather than working *with* them. A generation ago, the idea there might be a better approach to delivering care than doing what trained, well-intentioned people thought was best would not have been contemplated. But times are changing, and researchers and health-care providers are increasingly aware that patients and their families are experts in experience, with knowledge and insights that are essential for effective care.

The challenge we face, however, is how best to integrate what patients and families have to tell us with other sources of information and data to allow researchers, policy makers and providers to shape care in ways that are effective and responsive but also based on solid evidence.

This project, “Hearing the patient voice: Improving health care for people with complex mental health disorders in Saskatoon” was conducted under the Canadian Institutes of Health Research’s Strategy for Patient-Oriented Research.¹ It’s designed to foster innovative evidence-based approaches to managing health issues by opening up traditional research teams to include patients and others as equal members.

The principles of the Strategy for Patient-Oriented Research, described on the Canadian Institutes of Health Research (CIHR) website, include a multi-disciplinary approach. But the idea is to go beyond the usual concept of “multi-disciplinary,” where different academic and professional interests may be represented, to include the voices and knowledge of a broad range of stakeholders.

Most important, perhaps, is the requirement to include patients in all aspects of the work, to ensure research reflects the reality of people it is intended to benefit, and keep research questions and results relevant.

The strategy also calls for full involvement of decision makers and policy makers, representatives of health authorities, community organizations and even charities or private-sector organizations throughout the process, to help ensure research findings are integrated into policy and practice.

CIHR also requires that research funded through the strategy gets matching funds from other levels of government, to show that the research is considered relevant and applicable, and for the same reason requires it to be focused on outcomes, with performance measurement and evaluation as integral components. In our case, the Ontario Ministry of Health and Long-Term Care and the Saskatchewan Ministry of Health together matched CIHR’s \$80,000 grant, for a total of \$160,000.

There are multiple networks working under the Strategy for Patient-Oriented Research, each focused on a particular health problem or service. Our research was conducted as part of the Primary and Integrated Health Care Innovations network,² and took a close look at people with complex mental health and / or addiction issues who are frequent users of health care. Our work follows a growing trend of focusing on frequent users of health care services, whom research shows are often people with complex health problems, who seek care again and again because their needs are not being adequately met.

¹ Canadian Institutes of Health Research. Strategy for Patient Oriented Research. Available at <http://www.cihr-irsc.gc.ca/e/41204.html>. Last updated 2016-07-25.

² Canadian Institutes of Health Research. Pan-Canadian SPOR Network in Primary and Integrated Health Care Innovations. Available at <http://www.cihr-irsc.gc.ca/e/49554.html>. Last updated 2016-09-25.

Another requirement of the Strategy is that a minimum of two provinces work together, to promote collaboration and the sharing of knowledge and skills across provincial borders. In our project, researchers from Saskatchewan and Ontario used similar administrative data (specific to each province) and methods as the starting point for our work. Another benefit of the collaboration is that if the two jurisdictions produce similar results, that helps to validate the approach and findings — and that was the result of our parallel work with Ontario.

The overarching vision for this research was to have three complementary pieces, each of which would gather information from a different source and use it to create a more holistic picture of the reality of mental health and addiction care in Saskatchewan. The first piece was to analyze administrative records from health services to determine what kinds of care the most frequent users were seeking. The second piece was to create an inventory of mental health and addiction services to understand what services are available. The third piece was to engage with patients, families and front-line mental health workers to understand their experience of living with and treating mental health and addiction issues, and why or why not some services are used. An overview of each piece and its process is described in the next section.

II. DESCRIPTION OF THE RESEARCH

1. OBJECTIVES

a. ADMINISTRATIVE DATA ANALYSIS

The first step in our research was to review data from provincial health services records to determine who among patients treated for mental health or addiction issues were the heaviest users of health services. Previous research by us and our counterparts at the Institute of Health Policy, Management and Evaluation at the University of Toronto had shown people with mental health and addiction disorders make up a substantial proportion of most frequent users of health care, so we jointly decided to focus on that group. We were looking for shared characteristics that might help us understand why some people require so much more care than others with similar health problems.

We retrieved information by searching for mental health and addiction diagnosis codes. All patient names and other details that would identify them are hidden — instead, each record has an encrypted number attached, created by using a computer algorithm to scramble health card numbers so they're unrecognizable.

We planned to use any patterns we could see in the data to help develop more effective ways to keep people who are frequent users of health services healthier and using the system less, which would reduce health care costs. Combined with our discussions with patients, families and front-line providers, the patterns might also highlight ways to improve mental-health services.

Three specific analyses of the administrative data were planned:

- Screen for patients with different types of mental health and addiction disorders and describe their socio-demographic characteristics, illnesses, and use of health services;
- Develop methods to describe trajectories of those patients' likely use of health services and their outcomes over multiple years; and
- Create a statistical model to help health care providers predict which patients are most likely to develop complex problems that will require more help.

In this document we describe the methods and results for only the first objective.

METHODS

We and our counterparts in Ontario did separate but coordinated analyses of provincial health services databases to screen for records of treatments linked to mental health and addiction. Details of how we did that can be found in the Technical Appendix.

To screen for people who had been treated for mental health and addiction problems, we looked for individuals who ever had a physician visit or hospitalization that resulted in a mental health and addiction diagnosis code in their health record.

The next step was to calculate the cost of care among the people that the process identified during the

fiscal year from April 1, 2009 to March 31, 2010. We did that by tracking their physician visits, hospitalizations, prescription drugs and whether they lived in a nursing home. Details of how costs were calculated can be found in the Technical Appendix. Then we ranked the group of patients we had identified from highest to lowest cost users. The high-cost group was the most expensive 10 percent, and the low-cost group was everyone in the bottom 50 percent. Moderate-cost users were the group in between.

The next step was to calculate each person's health services cost for the next four years, to fiscal year 2013/2014, and determine if they were among the most expensive 10 percent in each of those years before assigning them to one of these categories:

1. persistent high cost users (a high cost user in every year);
2. decreasing cost users (a high-cost user in the first year with decreasing costs over time);
3. increasing cost users (a lower cost user in the first year who became a high-cost user over time);
4. sustained low- or moderate-cost users.

RESULTS

Our work found that out of approximately 800,000 residents of Saskatchewan aged 18 and older, 206,350 people (25.8%) were treated for a mental health or addiction disorder between April 1, 2007 and March 31, 2010. These people visited a physician over a million times in these 3 years. The most common reasons for these visits were anxiety (27.8% of all visits) and depression (29.3% of all visits). We found that nearly 70% of all health care costs in this year were attributable to less than 17% of people. Between April 1, 2009 and March 31, 2010, total health costs for them averaged \$14,000, more than 100 times as much as low-cost users (\$130) and 10 times as much as moderate-cost users (\$1,400). Compared to individuals who were persistently low-cost users, persistently high-cost users were more likely to have a diagnosis of a psychotic disorder. The most costly users were also more likely to:

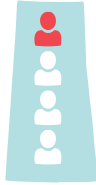
- be older,
- be female,
- have a chronic health condition aside from their MHA issue.

See Figure 1 for an overview of the results of the data analysis.

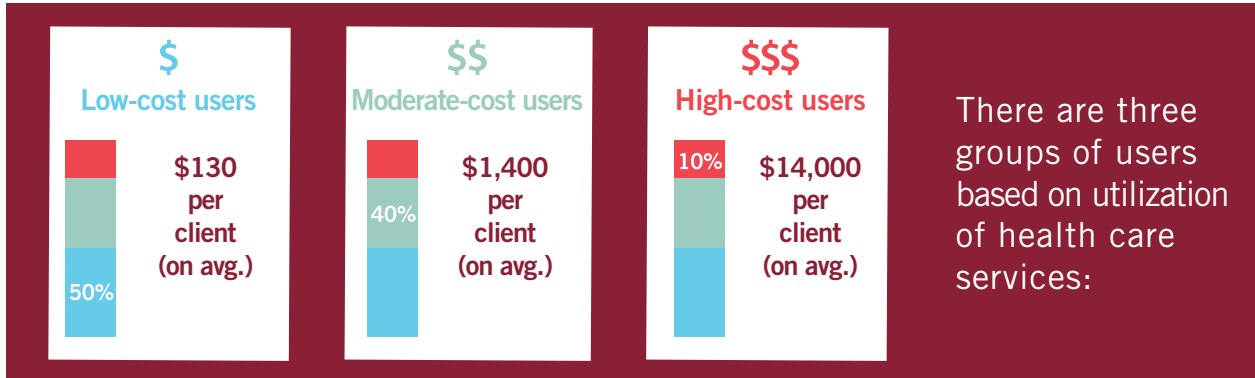
When we compared our results with those from our Ontario colleagues, we found our conclusions were similar. By far the most expensive diagnoses under the general heading of mental health and addiction were psychotic disorders.³ The mean cost for a person with a psychotic disorder between April 1, 2009 and March 31, 2010, inclusive was \$6,000. The mean cost for all other mental health diagnoses in that time was \$3,200. That difference is why we focused on services specific to psychotic disorders.

³ Psychotic disorders affect the mind and cause a person to lose some contact with reality. They may have disturbed thought processes and experience hallucinations (seeing or hearing things that are not real) and delusions (false beliefs). Retrieved June 2, 2017 from: National Institute of Health. What is Psychosis? Available at: <https://www.nimh.nih.gov/health/topics/schizophrenia/raise/what-is-psychosis.shtml>.

High-cost health care use in Saskatchewan: A picture of mental health



About **1 in 4** Saskatchewan residents aged 18+ have a **mental health** or **addiction** disorder.



High-cost users are the **smallest user group**, yet account for over **70%** of health care **costs**.



Psychosis is a **rare** but **cost-intensive** mental health and addictions disorder...



... and people with **psychosis** are over **4 times** more likely to be high-cost users.



But, by treating high-cost users with psychosis with the **right care** at the **right time** based on their needs...



... we can **utilize** health care **resources more efficiently** and **improve** their **quality of life**.

FIGURE 1: Understanding the costs of treating mental health and/or addiction issues in Saskatchewan in fiscal year 2009/10.

b. STAKEHOLDER CONSULTATION

As we mentioned earlier, the Strategy for Patient Oriented Research requires researchers to involve patients as equal members of the research team in all stages of the work. It also calls for decision-makers and clinicians to be included, to increase the chance the research findings get integrated into policy and practice. Because of that, we talked with stakeholders throughout the 12 months of the project, more intensively from July to October 2016, once we had focused on individuals with psychotic disorders as the subjects of the study. What we wanted from these discussions was:

- To familiarize the research team with mental health services available in Saskatoon Health Region⁴, and collect information for the inventory of services;
- To connect the research team with patients, families, and service providers so we could learn from people who live or work with mental health problems every day;
- To let the community know about the research project;
- To gather preliminary data on gaps and barriers in mental health care, as well as ideas for improving it.

Dr. Cory Neudorf, a member of the research team and Chief Medical Officer of Saskatoon Health Region at the time, developed an initial list of key people and organizations that should be contacted for input. Every person or group we consulted was invited to recommend others we should talk to. This “snowball strategy” continued throughout the 12 months of the research project, until we had a list of stakeholders that included patients, family members, directors, managers and front-line workers from both the Saskatoon Health Region and community-based services. However, due to the limited time of the project, we could not talk to them all, which means we may have missed some important perspectives.

We began by talking, either in person or over the phone, to people and organizations working on mental health issues. All conversations started with us giving an overview of the project and hearing about their work in return. From there, discussions varied but included topics such as how to engage with patients, what services were key for supporting patients with complex mental-health needs, what barriers patients face trying to access services, system barriers that get in the way of providing effective services, ideas for improving issues with mental-health care, and possibilities for ongoing support and consultation between the research team and the individual or organization.

c. THE MENTAL HEALTH SERVICES INVENTORY

At the start of this project we intended to inventory all organizations and programs in Saskatchewan that provide support services to individuals with any type of mental health or addiction issue. The sheer volume of services in the province made that impossible for a project of this size. Thus, after the administrative data analysis identified psychotic disorders being associated with a disproportionately large share of health service costs, we narrowed our focus to people with these disorders living in the most populous health region in the province, Saskatoon.

We wanted to make a list of mental health services for a number of reasons. First, it would help us identify

⁴ Saskatoon Health Region amalgamated with all the other health regions in Saskatchewan to form the Saskatchewan Health Authority in 2017.

gaps, overlaps and duplications in care. Second, it had become clear through our conversations that not all organizations and individuals involved in mental health care were aware of all the services available for care, and a comprehensive list would help with that. Better knowledge of community services could help avert the kinds of crises that cause people with psychotic disorders to require hospital and physician care.

The scan began with an online search of programs and services in Saskatoon. Next we met with the managers and directors of the health region's mental health and addiction services who described what they did and what organizations they worked with, which we added to the scan. The names of more community organizations were added after a follow up meeting. All told, we made contact with 10 of the most well-known mental health service or community support providers in Saskatoon.

Then, once we had decided to focus on people with psychotic disorders, we abandoned the full inventory and went more in depth, setting up meetings with many of the programs and services on our list who support this population. Again using snowball sampling, we got the names of more organizations in each meeting and set up meetings with them. We were able to set up meetings with 10 of the 14 organizations identified.

One important organization that was not identified through the snowball strategy, but which we considered an integral component of mental health care in Saskatoon, was the region's First Nations and Métis Health Service. There appears to be a lack of awareness of this organization and the cultural support it provides to the First Nations and Métis populations in the city. We discuss this issue later, in the Indigenous populations and perspectives section of this report.

The incomplete (abandoned) inventory of all mental health and addiction services in Saskatchewan still exists in an electronic draft form and is stored at the Health Quality Council.

We developed descriptions of the programs and services we learned about. The organizations were asked to review them but not all did. The descriptions can be found in the Technical Appendix.

d. THE ADVISORY GROUP

As consultations continued and we began to amass more and more information, we decided we had to go beyond individual consultations and bring together a select group of advisors to give us feedback on what we were learning. We felt a face-to-face discussion could spark deeper insights and help build community and share knowledge among our stakeholders.

It was particularly important to us to have an opportunity to bring patients and family members together with service providers, researchers and front-line workers. Patients and family members possess knowledge and expertise that give context and depth to data and professional perspectives. The information in this study is richer because of the perspective of lived experience only patients and families can provide. The advisory group was ultimately composed of three patient and family advisors, representatives of five community organizations, and nine employees of Saskatoon Health Region from five departments.

At a half-day meeting, we asked the group of advisors to consider and discuss the information from the environmental scan, the preliminary results of the administrative data and the consultation process. We also wanted to hear about their personal experience and knowledge. Our objectives were to:

- Identify gaps and barriers in services for people living with psychotic disorders in Saskatoon; and

- Provide recommendations on how to address current gaps and barriers to serve this population's needs more effectively and appropriately.

Suggestions and comments from the meeting can be found in the Technical Appendix. They are from a cross-section of stakeholders at a moment in time and are not meant to be definitive. Rather, we see them as a starting point for a conversation about what could be done to improve health care for people living with complex mental health challenges in Saskatoon. We hope they will stimulate partnerships across sectors, encourage the inclusion of patients and family members in planning care and services, and lead to continued conversation and more effective, integrated quality care.

GROUP MEMBERS

The service providers in the group were identified by the project coordinator during the scan of support services for patients in Saskatoon with psychotic disorders. Finding patients and family members has to be approached carefully to minimize experiences of tokenism and other false levels of patient engagement. Specifically, tokenism occurs when a token effort is made to appear to engage patients but the patients are not empowered to be meaningfully involved.

We used three different approaches for finding patients and family members; all of them involved using intermediaries who were trusted by the individuals approached. We asked Client and Family Centred Care at the Health Region to help us find a patient and family advisor who would be willing to join us, and in January 2016 one became a member of the research team, and a member of the group of advisors. The Schizophrenia Society of Saskatchewan Partnership Project connected us with a family member, and a manager from mental health service provider connected us to a patient who was a member of the Patient and Family Advisory Council at the Irene and Leslie Dubé Centre for Mental Health.

THE PROCESS

The face-to-face meeting of the group of advisors was held October 12, 2016. They had been sent an information package in advance, which gave an overview of the CIHR-funded research project, preliminary results of the data analysis, the in-depth environmental scan, and the summary of gaps, barriers and improvement ideas from our conversations with key informants. At the meeting, the advisors were asked to draw on their unique perspectives and experiences to provide feedback on the research, and to further identify gaps, barriers, and improvement ideas they could see that might lead to more effective and appropriate care.

Kyla Avis, from KDA Consulting, facilitated the four-hour discussion and Joelle Schaefer, the project co-ordinator, recorded notes from the discussions. The meeting started with a round of introductions, followed by a presentation by the primary investigator on the research grant, Jacqueline Quail. Participants were invited to ask questions or make comments on the research project and findings, before being invited to find partners (“pair and share”) to talk about gaps and barriers they thought had been missed in the consultations.

Gaps and barriers from the consultation process were posted on the walls for group members to review, and they were given sticky notes to add others they came up with. In a second round of pair and share, participants were asked to suggest solutions for specific gaps or barriers. When the exercise was done, the ideas were sorted into themes:

- Emergency department optimization
- Acute care / inpatient services
- Care transitions
- Enhanced community care options
- Service integration / seamless care delivery
- Education / training / awareness raising / support groups, and
- Other

At the end of the meeting participants expressed interest in continuing discussions and finding ways to work together to move these ideas forward.

Within two weeks, notes on the meeting, including both raw information and the themed classification, were sent to the group members to ensure the content and intention of their discussions were correctly captured.

SUGGESTIONS FOR IMPROVEMENT

The following suggestions emerged from the six themes identified at the advisory group meeting. They were ranked by the group after the meeting, starting with the most pressing:

1. Continue to implement the recommendations in the Mental Health and Addictions Action Plan endorsed by the Saskatchewan government in 2014. (<http://www.saskatchewan.ca/government/news-and-media/2014/december/01/Mental-Health-Action-Plan>)
2. Improve emergency care for people with acute psychiatric illnesses. For example, setting up care pathways in emergency departments to address their needs and ensuring providers are trained in emergency mental health care.
3. Co-locating multiple services would be helpful to reduce transportation and physical challenges to accessing services. For example, Saskatoon Health Region mental health services could be co-located with Government of Saskatchewan social services and community organizations in an easily accessible, patient-friendly place.
4. Enhance transitional and supportive care services. For example, complement the inpatient services offered at the Dubé Centre by enhancing the transition unit at the Dubé Centre or opening a day hospital. Services tailored to the needs of individuals are required to bridge the gap between acute and community care.
5. Improve integration of mental health and psychiatric care into the primary health care setting in ways that truly reflect patient needs and enhances their experience. For example, provide additional resources to support Westside Community Clinic in becoming a true patient medical home⁵ with enhanced mental health services and psychiatric care. The Lighthouse could partner with the Westside Community Clinic to provide outreach services with a focus on improving medication management.

⁵ A patient medical home is a family practice that provides seamless health care services that meet patients' needs throughout every stage of life within their community and integrated with other health services. Retrieved April 24, 2018 from: The College of Family Physicians of Canada. Available at <http://patientsmedicalhome.ca/>

6. Build on current, effective strategies of provider and public awareness campaigns and initiatives in Saskatoon to reduce the stigma of mental illness and add other communication mechanisms to raise awareness and understanding.

Other suggestions include:

- Break down communication barriers among service providers by facilitating face-to-face meetings between community organizations and the health region.
- Identify gaps in care and duplication of services between service providers.
- Identify additional service organizations and individuals who should be involved in improving mental health care in Saskatoon.
- Form a group of advisors to continue work on improving health care for people in Saskatoon with complex mental health issues whose needs are not being met.

The raw information on gaps and barriers, as well as improvement ideas, generated by both the consultation process and the group meeting can be found in the Technical Appendix.

2. INDIGENOUS POPULATIONS AND PERSPECTIVES

Throughout the process of creating the group of advisors and developing the suggestions for improvement, we were aware we were not hearing Indigenous People's views. We shared the results of the advisory group meeting with Saskatoon Health Region's First Nations and Métis Health Service. The group said developing cultural competency and creating psychological safety should be included as recommendations, and suggested training staff in them was something that could be done.

Also, while the group felt psychiatrists largely do an excellent job, the First Nations and Métis Health Service finds Indigenous People have trouble relating to and connecting with psychiatrists and other health care workers who do not fully understand the impact of deep-rooted issues, such as colonialism and the lasting trauma from the residential school system.

We recommend the Truth and Reconciliation Calls to Action should be used to support the work of the group of advisors and be included in actions for each suggestion where appropriate.

3. PATIENT INVOLVEMENT

CIHR's Strategy for Patient-Oriented Research places patient and family perspectives at the forefront of the research it funds. The need for patient and family engagement does not end with the completion of the formal research project. We recommend that patient and family advisors always be engaged in meaningful ways in all work that arises from this project and report.

4. NEXT STEPS

The funded portion of this project is complete but research activities are continuing to build on our work.

- The Health Quality Council supports ongoing work and plans to allocate resources to the research and continued development of the group of advisors.
- The Saskatchewan Centre for Patient-Oriented Research⁶ identified mental health and addiction issues as a research priority in 2017/18 and continues to support research in this area. The research team and the advisors could be resources and team members on new projects.
- Further analysis of the administrative data on frequent users of health care services with mental health issues was done by a PhD student.
- We are looking at more detailed collaboration with the Ontario research team on people with complex mental illness in each province who are frequent users of health care services.

We have some suggestions to support efforts to improve care for people with complex mental illness in Saskatoon. They are:

- The response to this report by the Saskatchewan Ministry of Health and any activities that spring from it should be informed by continued involvement and input from our group of advisors, although the composition of an on-going group will likely change—the group, for example, suggested it would benefit from including two psychiatrists who are recognized as leaders in the region and strong patient advocates. As well, an advisor from First Nations and Metis Health Service would bring an Indigenous perspective, as would inclusion of cultural support workers and Indigenous staff from the region's Mental Health and Addiction Services.
- Our work revealed considerable conflicting information about complex mental health care in the region. That suggests a lack of communication among organizations, a lack of knowledge of the programs available and a need for organizations to work together. More should be done to link these organizations, which have traditionally operated separately.
- We plan to share this research with multiple agencies in Saskatchewan, including the Saskatchewan Ministry of Health, the Saskatchewan Centre for Patient-Oriented Research, the former Saskatoon Health Region that has now become part of the Saskatchewan Health Authority, First Nations and Métis Health Service, community-based organizations, and the general public. As well, these results will be shared with the Ontario research team and their partners, and the Canadian Institutes of Health Research.

⁶ The Saskatchewan Centre of Patient-Oriented Research (SCPOR) is a partnership of organizations that support patient-oriented research in Saskatchewan. Retrieved April 24, 2018 from: The Saskatchewan Centre for Patient-Oriented Research. Available at <http://scpor.ca/>



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