Saskatchewan Institute of Health Leadership
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Final Group Projects
Accountable Healthcare Team: Palliative Pediatrics Services

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Introduction

As individuals who both access healthcare services and work within the healthcare sectors, we can all agree that there are positive aspects and also areas where innovation and improvement are required. In practice, we have witnessed first hand the gaps in care and challenging situations experienced by clients and their families during their healthcare journeys. In a system where daily struggles with funding can often steer a focus toward crisis management, bringing about positive change and providing holistic client centered care can be difficult. In working with families and children with chronic and life threatening conditions, this especially hits home. Many of us can say that we have either been directly impacted personally or professionally, or know families that are dealing with these unimaginable situations. Families not only contend with the daily struggles, but also deal with heartbreak when a child’s condition becomes life threatening or a terminal diagnosis is given.

Families and children in these cases should be met with understanding, empathy and the utmost regard. Healthcare planning should involve families directly and be provided by professional and skilled individuals to assist in navigating this painful journey. Socioeconomic status and family support systems should be considered during the planning process to provide quality care tailored to family needs. Currently palliative services provided to children with chronic conditions and their families are consistently inadequate in both urban and remote settings. Moreover, the transition that children and their families experience from the acute care setting into the community is lacking in planning, resources and service delivery which in turn affect outcomes and ongoing success. Raising awareness and advocating for more quality and specialized child and family centred palliative care is essential in improving quality of life and health outcomes of children. In exposing gaps and utilizing the perspectives of families and healthcare professionals, through our project research, we come closer to bridging those gaps and finding solutions to ensure the provision of holistic, family-centered, and quality care.
Background

To assess this issue, identify gaps and start the process of planning for positive change, we must first understand and define palliative care. The World Health Organization (WHO) has the most current and encompassing views on palliative care for children. The WHO believes that palliative care should "Improve quality of life of patients and their families" (WHO, 2018, para. 1). It is necessary for healthcare professionals to "evaluate and alleviate a child's physical, psychological, and social distress." (para. 4). Further, "Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited." (para. 4). This signifies that effective palliative care is holistic and encompass the family and community. Despite traditional views, palliative care applies to children with chronic conditions and not just at the end of life or when conditions become life threatening. Palliative care applies to pain management, but also to increase quality of life and improve care delivery for children and their families (WHO, 2018). There needs to be a focus on access to quality care and planning for the future, counselling, financial planning, respite services and general support to help families cope.

Throughout our research and planning phases and as health care professionals currently involved in providing services to families, we can all agree that Saskatchewan families above all deserve; patient and family centered care and planning, focus on quality of life, active compassionate care and a team approach. The Canadian Hospice Care Palliative Care Association (2013) shares similar beliefs and cites ten guiding principles of palliative and hospice care as person/family centered, ethical, high quality, team-based/circle of care, safe and effective, accessible, adequate resources, collaborative, advocacy-based, evidence-Informed and knowledge-based.

In preparation for planning and developing strategies to assist these children and families it was necessary to assess the available resources, current practice and gain insight from professionals and families currently navigating the system. Few studies have been conducted to assess the effectiveness of the current system and the impact on families and
paediatric patients. Ciemins and colleagues suggest that "To provide truly patient-centered palliative care services, there is a need to better understand the perspectives and experiences of patients and families. Increased understanding will provide insight into the development of health care team competencies and organizational changes necessary to improve patient care. According to patients/families, health care providers must be compassionate and empathetic and possess skills in listening, connecting, and interacting with patients and families." (Ciemins et al., 2015, para 1). It became very clear that taking into consideration the client and family experience was crucial in preparing to bring about positive change and truly impact lives.

**Methods**

Qualitative research challenges us to listen and hear the voices of participants. Through interviews as a research method we acquire a different way of knowing and understanding the experiences of patients, their families, and professionals working in the healthcare system. Using qualitative methods, we prioritize the person and their contextual experience, it allows participants to have a voice and to feel empowered. Silence perpetuates suffering, creating distress impacting patients and their families. The human side of the healthcare system can be captured by sitting down, listening and acknowledging the suffering in the stories told.

Overall, six interviews were conducted, and participants signed consent forms. We contacted key people knowledgeable in paediatric palliative care in the healthcare system such as two physicians specialized in palliative care, and two homecare registered nurses. We chose to interview these specific professionals as they are currently the frontline workers trying provide adequate care to palliative pediatric patients using a currently flawed system. It was also essential to share the perspective of a family experiencing paediatric palliative care services with their child. We attempted to meet with multiple families and unfortunately due to uncontrolled circumstances were unable to include multiple experiences and perspectives. We were fortunate to establish rapport and obtain insight from a family going through a very
difficult time with their infant son, who was diagnosed with a very rare and life threatening
condition. The shared experiences from this family further solidified our findings regarding the
current gaps in care and the need for innovative new pediatric palliative care trends. As we
were interested in applying the use of an accountable care team to pediatric palliative patients,
we first needed to understand what an accountable care team looks like and how one works.

To gain insight into accountable care team functionality, we interviewed the Director of
Pharmacy Services with the former Regina Qu’ Appelle Health Region who shared useful
information from Unit 4A at the Pasqua Hospital that has transitioned into being a fully utilized
accountable care unit.

Through these interviews, our findings can create innovation in the healthcare system
by providing recommendations meeting the needs of palliative paediatric patients and their
families.

Findings
The questions developed by our team touched on the areas assisting in identifying gaps,
determining how best to support families, and ensuring that their experiences and voices were
at the forefront of advocating for a more effective system of care.

Family Experience:
The Trudel family shared their journey caring for their child within the healthcare system during
an interview on January 18, 2018. They described their journey as a "rollercoaster", expressing frustration in how the system is currently structured. There are consistently wait
times interfering in care, and parents must attempt to keep track of multiple aspects of care
with little support from the system. Further, there are numerous health professionals involved,
but an overall lack of communication and collaboration among healthcare providers.

The family felt that every specialty was "only looking at their area and so if you don't
have someone looking at the situation as a whole it is not effective, especially with Thomas
being so complex". They felt care is inefficiently and ineffectively provided when a patient has
a complex case. Progress was often halted while waiting for one specialty. For instance, at the Royal University Hospital it took three to four weeks to see an ENT, during this time further care and investigation was at a standstill. This created distress for the family and child while they waited for answers, continued planning and care.

Through their healthcare journey, the family felt they were given an unrealistic picture of their child's condition. Some professionals implied that if one issue was corrected Thomas should be ok or would be much better. When they were transferred to the Edmonton Stollery Hospital they were shocked and devastated to be approached by ASSIST (Aid for Symptoms and Serious Illness Support Team) for further investigation as ASSIST is a palliative care team that works with families. The team told the family that unfortunately the long term prognosis for their child was not hopeful.

The family discussed their experiences with the healthcare system in the management of their child’s in both the acute and community settings. They expressed that very little services are provided by Home Care in Prince Albert to children- "Home care was only able to provide minimal time and the hours were not realistic for Thomas and his needs". Many barriers such as funding and lack of direction in the management of their child’s care presented when trying to plan to care for their child at home. The reality of him coming home looked very bleak and this was distressing for the family. Thomas’s parents stressed the importance of having access to the complex care Nurse Practitioner in Saskatoon and described it as being vital to their journey. They felt she kept everything together, made inquiries and investigated into aspects of care that they were unfamiliar with. The Ronald McDonald house was also identified as a very positive resource standing out as a great support service to them throughout their experience. Finally, the family described encountering a few great professionals going above and beyond their own job descriptions to assist the family and show them kindness and compassion.

After being linked with the complex care Nurse Practitioner (NP) and Social worker a few months into their child's life they aimed to access individualized funding (IF) through the Ministry of Health. The family soon found however that utilizing this funding was unfortunately
very complicated. They also added that “with the whole individualized funding having someone who had more knowledge on that, that is probably Home Care’s area” They looked into options for paying an in home caregiver as their child’s needs were complex. This entailed having to start a new business, hire and fire staff that would be responsible for their child’s life at home 24/hr per day at a wage of approximately $15.00/hr.

In sharing their experiences the family would like some changes to be made to improve the current system in the provision of pediatric palliative care. They were concerned that the palliative care services and planning were not as readily available to children and states: “This kid has a whole life to live, help him to reach his potential doesn’t make sense if your going to have it for elderly you should certainly have it for children. Why don't we take this kid and do everything with him so he reaches his full potential. By not doing anything it just costs money hand over foot”.

Access to Respite services, ability to access and utilize after hours nursing and medical care, and the ability to tailor planning to each individual child and their condition were proposed by the family to improve the current system of care delivery. Thomas’s mother Shianne stated “It would be nice if Prince Albert had a little more options to avoid trips to Saskatoon, more resources and options here. Someone if anything could be changed learning from things the respite, homecare, for kids with high needs. ” It was abundantly clear during the interview and the parents identified that above all there needs to be more effective communication between professionals and teams involved in the care of these children and their families. They also stressed the importance of the need for care involving looking at the whole picture. Discussing that the health care providers deal with so many children and cases the father added “I think the nurses and doctors forget that this a big deal to the parents.” They described the Nurse Practitioner, as being a navigator of the system for them and a vital part in their overall experience in caring for Thomas. They state: “ there absolutely needs to be somebody who is the quarterback, that’s not even a question, it saves the province money, and someone that is helpful to the family. It doesn’t even need to be a nurse practitioner as long as there is someone with education that's good at facilitating coordinating all of the and overlooking”
From this family testimonial it became exceedingly clear that Saskatchewan children with chronic conditions and their families deserve more patient and family centered care and planning, a focus on increasing and preserving quality of life, active continuous compassionate care, and there should be a team approach to assist families in navigating the system. In providing families with a more compassionate care, overall support and quality planning for success in the future, the need to access acute care services could be drastically decreased as families potentially would be better equipped to cope and manage throughout this difficult journey.

Health Professionals’ Perspective:

As we continued on the journey of navigating the current system, it became very clear that we would need to involve the perspectives of professionals directly involved in providing these services to children and their families. These professionals play a vital role in assisting families in navigating the system, providing direct medical care and planning for children with chronic conditions, providing or linking families with emotional/social support and focusing care to ensure overall quality of life. The professional perspectives involved in our research include a multidisciplinary focus to ensure the involvement of both acute and community care sectors.

One of the most crucial perspectives involved in identifying gaps and future planning in the area of pediatric palliative care is Dr. Hodgeson-Viden, the Palliative Care Specialist working out of Royal University Hospital in Saskatoon. She works very closely with Hope’s Home in Saskatoon providing care and planning for the children who reside there with medically complex conditions. In an interview with Dr. Hodgeson-Viden she described her role as “providing support and to help coordinate palliative care services for children across the province.” and discussed the current system stating “Saskatoon has a Palliative Home Care team, but professionals have no formal pediatric training. In Regina the home care team are pediatric focused but have no formal palliative care training. The palliative care unit in hospital will only accept children if they are 16 or older, and the adult palliative care physicians have
no pediatric teachings.” Dr. Hodgson-Viden shared that “the Pediatric Unit in Saskatoon can now run infusions which helps with the end of life transition and the ability to care for children”, as previously “children were admitted to Pediatric Intensive Care Unit (PICU) in the past, creating an unpeaceful environment.” She felt that the gaps in care and short falls included an overall “lack of social work resources”. Families in Saskatoon depend on two pediatric ward social workers, one oncology and one home care social worker often making it difficult to navigate and organize care.” She added “overall more education and awareness is needed within the medical community. It’s okay to refer children before the end of life. Palliative Care can be provided for many, many years to children and families and a team approach would enhance quality of life for the child and provide support for the entire family.”

We also gained a very insightful perspective from Dr. Ramji, a pediatrician employed with the Prince Albert Victoria Hospital, who works very closely with Hope’s Home in Prince Albert providing direct care to children, many who have life threatening conditions. During an interview with Dr. Ramji on January 3, 2018, he described his role as providing Palliative care to children and families in the Prince Albert Victoria hospital as well as collaborating with other teams and professionals throughout the province to provide care and services to children with chronic conditions. Dr Ramji “believes that Palliative care implies comfort prior to passing away and DNR (Do Not Resuscitate) status”, however feels that “palliative principles need to be applied for children with chronic conditions at all stages.” He states “to wait until a DNR status is ordered to have access to palliative care is not right.”

In describing the current system he feels “the current system is not as effective as it should be with children and families waiting for extended periods in acute care for appropriate resources and planning to be put in place. Home care is able to assist with supplies and at times assistance with medications, however parents must be very knowledgeable and self sufficient to provide care at home. Deficiencies lie in the lack of process- as it feels with each new child/case we are starting all over again. In the current system we are lacking the continuing presence of skilled support people- not just with clinical skill, but social, spiritual and practical skill that can make things happen.” Dr Ramji believes that there should be access
to a group of multidisciplinary professionals province wide to assist planning and all aspects of care. He feels that necessities like respite beds and hospice care should be provided through certified centers, like Hope's Home. In closing he stated that he is “grateful that someone is looking into this area of focus, as he believes it is often neglected. He feels it is very hard to look at and deal with effectively as each new case that presents is highlighting these deficiencies in care.”

We wanted to ensure we assessed the available services in the main areas of the province and one such area is the pediatric services provided in Regina and surrounding area. We conducted an interview with Pediatric Home Care for Regina area on March 1/18. Currently, in the Regina area, professionals offer round the clock respite services to pediatric clients. They described “having noticed an increased need for pediatric palliative services in the area,” and “currently are working to grow and develop the existing program and improve collaborative care.” They believe that practitioners currently have good communication and the pediatric home care services program offers as seamless of an experience as possible to their clients based on services currently available. It was suggested that utilizing a provincial EMR system would significantly simplify admission into an acute care setting and vice versa. It was also identified that families would greatly benefit from having a Navigator as part of the care team, to take stress off of the family as coordinating appointments can be exhausting and navigating the healthcare system can be very intimidating. The role of a navigator would be to coordinate and facilitate all healthcare interventions, help guide families through the system with ease, assist families in applying for available government funding and would have the knowledge of what types of funding families are eligible. This suggestion is very similar to a recommendation provided by the family that we had interviewed.

It became very apparent that each area of the province has varying resources and areas of focus in regards to caring for with children with chronic conditions and the palliative care services provided. Through working at Hope’s Home in Prince Albert, providing care to medically fragile children, it was apparent that the home care services provided to children in the community, and across the province, are lacking. An RN at Home Care in Prince Albert
shared her perspectives on the current system. She explained what kinds of support are provided to pediatric palliative patients through the Home Care Palliative Program. Registered Nurses are available for home visits during the day, with the option to call backup during off hours. However, it is not usually a Palliative RN providing the care. They also provide physical support usually with dressing changes, tube feeds and medication support as well as ongoing health assessment and can be the contact for doctor and or specialist. They are able to provide caring empathetic support to the families and children.

Nonetheless, support for specialized cases is limited because of staffing and hours available. She explained it is difficult for families to access respite services and after hours care. It is not readily available and requires much preplanning. This is a current gap in care, palliative families are not well supported once in the community and fall through cracks in service. Further, she explained that numerous changes and improvements must be made in the system. Home care nurses are currently not fully involved in the child’s healthcare journey. They are not available for emergency, and not fully educated on special Palliative needs. She explains that their current staffing and education lacking, they are not equipped to provide sufficient palliative support for patients and their families.

Themes & Discussion

Finally, as we came to the end of our interview process and assessment of multiple perspectives regarding the delivery and utilization of pediatric palliative care services some clear trends began to emerge. From all of the interviews that we conducted, there was a consistent theme in issues being identified, such as poor communication between professionals and caregivers, lack of available resources (such as respite services and after hours care), the need for a team approach, and the use of a system navigator.

An effective way to meet the goals of collaborative care between all healthcare providers and have a patient centered approach to providing care would be to utilize the system of an accountable care team. This team based approach can be utilized for the majority of patient demographics with the makeup of the team members specialized for the needs of
that specific patient demographic.

An accountable care team is a microsystem to manage patient care environments to provide optimal care to patients in a reliable and repeatable way. The team consists of an RN/MD co-lead and the physician is centralized to that sole area. The team runs on daily routines, and by implementing and following these routines the members have built trust and accountability between one another. This creates a higher functioning team that’s capable of providing a higher level of care.

Currently this model of care is being utilized in the Pasqua Hospital on unit 4A. Since 4A has begun utilizing this care model, there has been a 17% decreased length of stay, along with increased patient satisfaction. (Patients are provided an optional survey to complete following their stay). Increased staff satisfaction has also been reported as it is felt that there are good lines of communication between all care providers and there is a daily opportunity for all team members to discuss anything that they may view as a potential issue in patient care from their professional perspective (i.e. pharmacists have the opportunity to discuss possible drug interactions, nurses don’t have to struggle to try and get ahold of the physician for new orders). The team has a team covenant that is regularly reviewed and re-signed by all members of the team to keep up accountability and awareness of the importance of working together. The 4A team’s daily routine consists of rounds involving all team members done at the bedside of each patient. Rounds are consistently started and finished at the same time each day, allotting the same amount of time to be dedicated to each patient. The consistent times allows for the patient’s family members to know what time they need to be there if they want to be included on the bedside rounds as well. A protocol is followed when completing the rounds to ensure that every team member is given the opportunity to report as well as the patient and their family is able to ask any questions. The bedside report is concluded with the care plan for the day, the estimated length of stay and projected discharge date.

Some challenges that may be encountered when trying to implement an accountable care team model may be current workflow operations, resources available, workload, and the culture of health care politics. Healthcare currently operates through a silo management
system, but if all health care disciplines can work on the same level as one another with the same amount of respect for each care provider a culture shift will begin and the level of collaboration between all professionals will increase over time as working in a team unit becomes the norm.

Considering the current gaps that have been identified for the pediatric palliative patient demographic, utilizing a province wide accountable care team would eliminate a lot, if not all, of the current communication barriers between care providers. This would also increase the family's awareness of the condition and needs of their child.

In the shared experience by the Trudel family one of the teams encountered during their journey was the Aid for Symptoms and Serious Illness Support Team (ASSIST) at the Edmonton Stollery Children’s Hospital. ASSIST is an example of an accountable care team designed around the needs of the palliative pediatric patient demographic, providing services to children and families in northern Alberta. The team is made up of physicians, nurses, and a counselor who offer: support when a child's illness is first diagnosed, help making decisions planning for care, care for a child who is dying at home, in hospital, or a hospice, and grief support for parents who have lost a child (Government of Alberta, 2018). Having a team of professionals proficient in both pediatric and palliative care will provide family with the peace of mind and compassionate support during one of the most difficult times in their lives.

Based on our findings, six key recommendations can be made to foster a new and innovative system of care delivery in the area of pediatric palliative care in Saskatchewan include:

1) Palliative services and resources must be provided for children and their families at the time of chronic illness or condition diagnosis, including prenatal diagnosis.

2) Families should be set up for success with access to and direct involvement in holistic care planning and regular follow up in hospital and in the community.

3) Assessing and modifying existing accountable care team models to fit needs of children with chronic conditions and their families in the province.

4) Selecting and assembling a provincial accountable care team to support children with
chronic conditions and their families province wide. The team will assist in coordinating care and aligning resources, accessing professionals and services close to family residence and support systems.

5) Implementation of mandatory pediatric and palliative care education for Home Care and community health agencies providing direct care to children.

6) Increased funding and access to vital services such as respite, after hours medical care and hospice for children, provided through Home Care or existing child care facilities provincially (i.e Hope’s Home).

The Provincial Accountable Health Care team proposed by our group will be based out of the new Children’s Hospital in Saskatoon. Professionals involved in the team would include a Pediatrics Palliative Specialist, Registered Nurse Practitioner, RNs and LPNs trained in palliative and pediatric care, Social Workers, Dietician, Pharmacists, and healthcare system Navigator. At the time of diagnosis of a chronic condition or terminal illness the child and family will be referred to the Palliative Pediatric Accountable Care Team that will provide an initial assessment and care plan that the team will follow through with on an ongoing basis for the child. The palliative pare Pediatrician will be involved in diagnosis as the first point of care, assist with coordination of care including all specialities, and be responsible for overall health management of the child. They will collaborate with the rest of the care team to develop an ongoing care plan.

Upon initial diagnosis families will be linked with the Social worker and system Navigator, who along with the team support, will be responsible for coordinating care and assisting family in obtaining access to financial planning, bereavement care and support services (therapist or counsellor), accommodations for housing, assistance in transition from hospital to home, the education system, and therapies (PT/OT/SLP). The Navigator would be local to the family and likely be based out of the local home care facility. They would act as the liaison between the family and the accountable care team and facilitate regular telehealth meetings between the family and the care team if an in person appointment was not required. Utilizing regular telehealth meetings would keep the care team up to date on the child, and
keep the lines of communication open for the family to have a regular opportunity for asking questions. This would also allow for families to travel into Saskatoon less frequently as the care team would still be able to ensure that the child’s condition is being managed in their home community.

The complex care Nurse Practitioner will lead collaborative team efforts in supporting families with pain management, assessment, and ongoing referrals. Nursing staff will provide direct care link with respite services, wound care, assessment and ongoing provision of care. The accountable care team Pharmacist will assist with medication management and ensuring the medications to be prescribed to the child are therapeutically suitable and do not have any contraindications with each other or any herbals and vitamins being administered at home. They will communicate directly with the pharmacy team at the child's community pharmacy to ensure any medication changes that have happened in acute care transfer over to home as well upon the child being discharged from the hospital. The pharmacy team at the community pharmacy will assist the family in ensuring available coverage is applied for. The Registered Dietitian will provide nutritional guidance and feeding/health plans to accommodate changing health condition ensuring that proper nutritional needs are being met. All care will be delivered with compassion and empathy, will be culturally sensitive and include sibling and extended family support.

Specialized training will be provided for each team member and filter down through to the rural centers in order to support children with chronic needs. Formalized training can be provided through workshops, distance learning opportunities, conferences, on-the-job training and cultural awareness training. A strong focus on advocacy is crucial to ensure that families and their children have the best possible quality of life.

In conclusion the healthcare journey of children with chronic and life threatening conditions and their families is full of heartbreak, uncertainty and often involves a painstaking struggle to obtain both support and necessary resources. The current system of delivery in relation to palliative services to children is not effective in supporting families. The gaps in care are extremely apparent and can be observed in all accounts, from the family experience
to the professionals providing direct care. In order to start to better support families, we must first rethink the definition of palliative care to encompass more of a lifelong approach. Access to palliative care services should begin at the time of diagnosis to better serve families and ensure more adequate support and long term success. Families and these children deserve a system of care that provides for the best possible quality of life, with compassion and empathy at the forefront. It is time for the health care system both on acute and community levels to adopt a more holistic and collaborative approach to providing care. The use of an Accountable Care Team taking the lead would allow for the best possible service delivery, helping families navigate through this difficult time in their lives, with access to resources for long term success in the community. Through use of this model, in the long run there will be more patient and family satisfaction. Utilization of a team approach will ensure all care providers are working collaboratively to improve the quality of life for children and families following a chronic and complex diagnosis. The Accountable care team in conjunction with local multidisciplinary teams will ensure that the family remains supported throughout their entire health care experience physically, socially, and emotionally.
References:

Canadian Hospice Care Palliative Care Association, (2013). A Model to Guide Hospice Palliative Care: Based on National Principles and Norms of Practice. Ottawa, ON: Canadian Hospice Palliative Care Association.


What can be done to ensure that the Saskatchewan Health Authority regionalization empowers the patient voice?
This project was designed to answer the question, “What can be done to ensure that the Saskatchewan Health Authority regionalization empowers the patient voice?”. In an attempt to answer this question, we conducted interviews with current and past healthcare leaders, stakeholders and reflected on available information and research as it ties with the leadership considerations we want to explore.

Our intentions for the project are to provide meaningful insight, recommendations, and considerations by the leaders of Saskatchewan Health Authority. Even though we focused our ideas and recommendations through the lens of patient family councils, we feel that the insight derived from our research should be considered throughout all aspects and levels of patient care in our newly formed healthcare system.

On January 4, 2017, Health Minister Jim Reiter announced that the province would move to consolidate the 12 existing Regional Health Authorities (excluding the northern Athabasca Health Authority), into a single Provincial Health Authority by the fall of 2017. This transition was based upon recommendations issued by the Saskatchewan Advisory Panel on Health System Structure.

It is reported that the goal of this move is to improve patient services across the province as well as to improve administrative efficiencies. Reiter proclaims the primary driver is to get rid of the arbitrary boundaries that have been affecting patient care.

In a message from the Ministers of Health, the transition into a single Provincial Health Authority is to ensure “that patients receive quality, timely health care, regardless of where they live in Saskatchewan” (Message from the Ministers of Health, 2017).

At the time of the launch of the Saskatchewan Health Authority, the mission, vision and core values were not yet defined. One can’t help but ponder what leadership lessons will be learned in this new era within Saskatchewan Healthcare. When there is change, there is opportunity.

Opportunity to do better and be better.
History of Regional Health Transformation and Evolution in Saskatchewan

Historically, Saskatchewan has played a leadership role in the development and evolution of the medical system in Canada. Medicare was born in Saskatchewan on July 1, 1962. It would be the first government-controlled, universal, comprehensive single-payer medical insurance plan in North America. Under then-Premier Tommy Douglas, Saskatchewan led the way to improved access to health care in Canada. In 1947, the province began paying for basic hospital costs for all Saskatchewan residents. The province’s program became the model for the national health-care plan. One can’t help but wonder, what leadership qualities worked well then and what type of leadership will work best with the current changes?

This recent healthcare transformative move is the latest in a long history of health region amalgamation within Saskatchewan. In 2002, the number of Regional Health Authorities (RHAs) was reduced from 32 to 12. Up until December 4th, 2017, Saskatchewan was divided into 12 RHAs, each with its own regional governing board and administrative operations. Additionally, Saskatchewan also includes the northern Athabasca Health Authority, which is administered jointly between the provincial and federal governments to serve the residents of the Athabasca Basin. Due to its unique status, the Athabasca Health Authority will not be included in the consolidation of RHAs.

Leadership Consideration – Vision, Mission & Core Values

The Saskatchewan Health Authority must recognize that a transformation would be more efficient once a clear vision, mission and core values are adopted and embraced in the culture of the healthcare system. Establishing a clear vision provides organizational destination and a roadmap for the strategic initiatives. The mission statement acts as the driving force on how to achieve these strategic initiatives and outcomes. It is important so that everyone involved in the SHA, including employees, outside stakeholders, and patients, understand what the organization will accomplish and how it will be accomplished. In essence, all parties need to be moving in the same direction to achieve success. Clear core values are essential in the standardization process across the health authority, as it provides a framework to which the systems must adhere to reflect the priorities of the organization. Several months into the transformation, there is still no clear vision, mission, and value statement.
Capturing the Patient Voice – Initial Stages of the Health Region Transformation

Saskatchewan residents and interested organizations were invited to provide feedback to the Advisory Panel examining the restructuring of Saskatchewan’s health care system during a period that was open to the public from August 29, 2016 through September 26, 2016. During the formal feedback period, the Advisory Panel held consultations with key health system partners and stakeholders, including health region leaders, health providers such as physicians, provider unions and affiliates, Indigenous leaders and others. In total, 339 responses were submitted to the panel including 258 individual responses and 81 responses reportedly provided on behalf of an organization.

Potential gaps in the initial capturing of patient voice:

- There were 1,158,339 people living in Saskatchewan as of January 1, 2017, according to the latest population estimates released by Statistics Canada. Only 0.0293% of the population of the province responded to the survey and had their voices included in the consultation process. The request for participation in the survey was not publicized broadly enough to create awareness for Saskatchewan residents. It was posted on the Ministry website, on individual health region websites and sent to health region employees, so there is a curiosity as to how many of the respondents were employees of the health regions.
- The time period for participation in the survey was very short – there were only a mere 38 calendar days to provide feedback for changes. During the survey period, the changes contemplated, the intent, expected outcomes, and risks were not communicated to the public in a way that would provide space for reflection, dialogue, suggestions or debate.

Leadership Consideration- Appropriate Consultation

The number of respondents was not sufficient to represent a fair sample size. Perhaps, the transition team should have recognized that they needed to enlarge their sample size and not proceed until they have captured a fair representation of the residents of Saskatchewan. As noted above, there was no transparency as to the demographics of the small sample size received. It is unclear if these respondents accurately represent diverse cultural groups, patients of all ages, various education levels, remote northern communities, rural and urban communities, various gender identification groups, different economic levels, the voice of the homeless, immigrants or those patients with specialized healthcare needs. Future surveys should reflect the collective voices ensuring adequate representation of cultural competence, diversity and inclusivity.
Patient and Family –Centred Care: Putting Patients First

Patient and Family-centred Care has existed as a philosophy in Saskatchewan since 2005. According to the Saskatchewan Government website, Patient and family centred care is described as: “providing respectful, compassionate, culturally responsive care that meets the needs, values, cultural backgrounds and beliefs, and preferences of patients and their family members in diverse backgrounds by working collaboratively with them.” As this has been in place since 2005, “Nothing about us, without us” is still not adopted throughout the former health regions. It is evident that there is still work to be done in this area.

The four core concepts of patient- and family-centred care are:
1. Dignity and Respect
2. Information Sharing
3. Participation
4. Collaboration

Leadership Consideration- The Patient Voice

Incorporating the four principles of Patient and Family Centred care into the patient experience remains an area of opportunity for SHA. Upon consultation with health leaders and informal conversations with patients, there is still a gap regarding how this is truly engrained in what we do.

Going forward, and soon in the journey, SHA needs to determine how to get the patient voice into strategic priorities and get the funding allocated to make this happen. Patient voices need to be setting the vision, mission and core values, and determine how our patient advisory groups will be connected and talking. It is easy to fall into the trap where the patient voices hold less value than the operational and bureaucratic voices.
**Advocacy vs Advisory**

When part of an advisory group, the patient brings their own health experience and their circle of influence—sometimes as advisory and sometimes as an advocate. We need to recognize where there is a misalignment between patient values and personal agendas versus the strategic imperatives of the organization. Advocacy and advisory stances don’t need to be mutually exclusive. There has to be a balance between the two. We need to recognize how to handle when there is a misalignment between the strategic priorities and where the resources are going.

**Leadership Consideration- Advocacy vs. Advisory**

There is an opportunity to put the patient and family voices into the work plan and strategies at the early stages of this transformation. Even if we don’t have the frameworks entirely in place, we need to bring patient and family voices to the table to actually fulfill the values we have been espousing.

The current advisory groups are not always aware of the provincial priorities, and there needs to be further training and education on this. We understand that there is education provided for PFAs across the province, but it is not standardized. This education varies greatly (web, face-to-face, hard copy materials, etc.) and standardized selection and recruitment practices need to be implemented across all groups.

Patients should be there to challenge the strategic plans; they should be building and shaping the provincial health vision and mission statements. Partnering and co-designing together are essential. Leaders need to use this data and feedback to drive change. We need to remember that what is a priority as an organization may not be the same as what a patient deems important.

Although biases are unavoidable, the selection process for PFA members should put more emphasis on screening members to assure that potential candidates with personal agendas are redirected to the appropriate groups and organizations that are more appropriate in an advocacy role. Having an in-depth screening process and providing education and training with very pointed questions will help assure that the best candidates, who are aware of the scope of their function, are chosen for PFA roles. This will lessen the need for future coaching.
Current mechanisms/organizations to capture the patient voice

Saskatchewan Centre for Patient Orientated Research (SCPOR)

SCPOR is a coalition of organizations that support patient orientated research in Saskatchewan. Currently, the focus is limited to mental health. With a limited scope, SCPOR utilizes PFA’s in support of research.

Leadership Consideration - Better access for Clients to SCPOR

Although it is favourable to see the patient voice is considered with provincially and federally funded health research, there is no clear understanding or public awareness regarding the role that the PFA plays in this organization. Better communication between client representatives and the general public is needed, as currently there is a disconnect between these two. It is unclear how the knowledge translation of this research will pass down to the front line staff and impact positive patient outcomes.

Patient and Family Advisor Program

PFA's have a unique opportunity for positive change in the current health authority amalgamation. Currently, there are PFA's across Saskatchewan, serving everything from small community interest to larger urban centres such as the Saskatoon Health Region. Presently, there are inconsistent terms of reference (length of terms, variances in honorariums, and recruitment practices) in almost all PFA's in the province. In discussions with leadership in Alberta we found that from a governance perspective, the genetic makeup of having one large health authority (Alberta Health services) has proved challenging. In the first few years of amalgamation, they found they did not have the infrastructure in place to allow for sufficient communication between PFA's from various geographic locations. Moving to a health care system that is divided into zones based on geography, allows for better communication and appropriate focus on the health needs of those specific areas.

PFA Standardization

In consultation with various partners and executives, it becomes evident that there was a need to have a clear and united provincial voice in the PFA system, while still recognizing that individual communities and voices need to be captured. Once a provincial framework for patient family-centred care is in place, the potential areas of standardization include, but are not limited to:

- Terms of reference
- Recruitment
- Compensation/honorariums
- Pool refreshment (length of terms, rotating end dates)
- Selection process and education
- Conflict of interest policies
- Standards that ensure cultural competence and inclusivity models

We also recommend increasing access and opportunities for PFA involvement by investing in technology such as Web-ex/Telehealth. Ensure adequate funding is in place to support this technological infrastructure. Also, create a database of shared PFA's data and experience collection.
### SWOT Analysis – As it pertains to capturing the patient voice

#### Helpful to achieving strategic priorities | Harmful to achieving strategic priorities
--- | ---
**STRENGTHS** | **WEAKNESSES**
- Amalgamation, the creation of SHA
- New dyad leadership structure
- The intention of Scott Livingstone (CEO) to include patient voice in all parts of the transition whenever possible, minimize barriers and identify challenges
- SHA plans not to re-create the wheel; plan to bring the advisory networks up to the highest standards, not the lowest standards.
- Active engagement with other provincial representatives to learn from their experiences and best practices.
- Patient First Strategy – patient voice included in strategic planning adopted 10+ years ago.
- Currently has a framework for patient family centred guiding coalition
- First province in Canada to adopt the open presence policy.
- The Mission, Vision and Core Values of SHA have not yet been approved and should have been an essential priority in the first stage of the transformation. How can you standardize anything without the core values of which you are standardizing?
- The system isn’t upholding their guiding value of patient and value care
- Funding and human resource challenges
- Limited opportunity for patients to give voice to their concerns outside of SCPOR or PFA advisory groups
- Current practices of capturing patient voices are inconsistent throughout former regions.
- Ministry and advisory councils work at a macro level, and strategic priorities may not identify or resolve gaps/issues important to the patients.
- There are still missed opportunities to bring patient voices to the table.
- Recruitment is a challenge (funding and resources for promotion) – diversity and broad engagement is a challenge
- Hard for patients to navigate the healthcare system
- Lack of transparency and patient access to their health information and options.

#### OPPORTUNITIES | THREATS
--- | ---
- Patients are vital partners in improving healthcare and need to be included when setting province’s healthcare priorities and setting the vision and mission.
- Partnerships to address social determinants of health across ministries
- Using technology as a means of connectivity (EMR, points of service, real-time feedback) at various levels and not just at acute level allows for easy and economical access
- To empower patients in their health journeys
- Prevention-focused activities
- Evidence and data to drive decisions on programming and services
- Use of community-based organizations and affiliates to capture the patient voice
- Adopt idea that patient is the final owner of their health information and decisions.
- Bridge gap between 3rd party and private healthcare and public healthcare information
- Allow frontline health care workers to have the ability to voice concerns/ideas about health management and quality of care.
- Adopt a patient first model of care that has standardized:
  - Conflict of interest policies
  - Terms of reference
  - Cultural competence policies and education
  - Inclusivity models
  - Recruitment strategies
- Demographics – there is no single way to capture the patient voice across all levels of service, geography, cultures, ages, education levels, etc.
- Expectations of stakeholders – Patience will be key! Change will take years to implement correctly.
- Patients often are only able to represent themselves and their life experiences and circles of influence.
- Cost
- Lack of engagement from population
- Lack of buy-in from SHA employees at all levels (from the front line to executive).
Leadership Lessons Learned

High-impact leadership is not just for senior leaders but is required at every level of healthcare delivery. Not only do health care professionals need to be leaders to ensure the successful transformation of healthcare as we know it in Saskatchewan, but it is equally important that patients are leaders as it pertains to their journey in the healthcare system. For patients to be empowered as leaders within their healthcare, they need to have a voice that is heard and considered in quality improvement initiatives. Engaging patients to capture their specific experiences and perspectives provides a different lens that can be used to look at common challenges. It allows for an objective stance on strengths and weaknesses and the impact on the care of patients. Using patient testimony and reviews can promote a common purpose and often spurs action.

Leadership Consideration - Patients as Leaders

Effective leadership ensures that the voice of patients is consistently heard at all levels—in particular both at the authority level and the ministry level. Frameworks and processes need to be put in place so that there are an understanding and balance between the recommendations put forth by patient advisory groups and that of the strategic priorities of the ministry. Patient experience, concerns, needs and feedback (positive and negative) need to be attended to consistently across the province. People are well-informed, well-educated, and they know best what they need and want.
KEY RECOMMENDATION

New Framework to Capture and Include the Patient Voice under SHA

In addition to the work that is currently going on behind the scenes (with SCPOR, HQC, and the PFA groups) which is not well known or readily accessible to the patients of Saskatchewan, it is also essential to embrace modern mechanisms for managing individual healthcare journeys.

We already utilize our devices to manage all aspects of our social and financial lives, so why shouldn’t we have the option to use our devices to manage our healthcare journey? Apps are a tool that is used for almost every daily activity. Currently, many people already have some type of health app downloaded on their device.

Transformation Recommendation – “SHA Healthcare Dashboard”

SHA should implement a “Healthcare Dashboard” – a patient portal that is accessible through web browsers and mobile apps to provide a next-generation patient experience and create active patient engagement. When you proactively engage patients in their care, the quality of that care improves. By understanding the growing popularity of patient portals (app and mobile platforms), their benefits, and their uses, healthcare organizations and providers can better leverage them to boost patient engagement through capturing the patient voice.
Benefits of Implementation of an “SHA Healthcare Dashboard”

1. **Increase patient engagement and empowerment**
   - The convenience of using an app increases patient engagement. Patients can engage at the lowest possible level, on a one-time basis, frequently or utilize the tool to find other opportunities to engage at the PFA level.
   - Patient engagement can be tailored to fit individual preferences or based on self-identification of the user.
   - Surveys can be distributed to patients on tablets/kiosks/Bring your own device (BYOD) before, during or after healthcare visits.
   - Engagement opportunities to provide feedback doesn’t have to be limited to surveys presented.
   - Link to telemedicine services with video or chat capability.
   - Patients will value having access to EMR (electronic health/medical records), booking appointments online, getting appointment reminders.
   - Allows for identification of patterns of patient populations who are and are not likely to utilize the patient portal. By identifying communities with lower adoption rates, SHA can target the current engagement strategies to encourage portal adoption, helping them to deliver better care to their patients in the long-run in addition to the paper formats.
   - The app would free up resources and reallocate time to focus on demographics or patient population groups that have lower rates of patient portal adoption, potentially due to lack of access to technology or lack of technology literacy.

2. **Increased data and analytics**
   - Autonomous, real-time data entry.
   - Potential to have more substantial sample size engaged and less cumbersome data collection than with paper surveys.
   - Opportunity to create a single database to collect patient voice – funnelled from the ground up to strategic priorities.
   - Ability to observe patterns and gaps in service.
   - Better data quality means better health decisions and better patient outcomes.
   - The potential to collect physiological data, contextual data (situation, preferences, and emotions), and usage data in mobile apps can be leveraged to provide useful insights and recommendations for new workflow efficiencies.

3. **Improve patient satisfaction and improve quality of care and outcomes**
   - Patients can stay informed about services available.
   - Research – patients can access a broader pool of specialists more efficiently without the boundaries of the health regions, and they can help find the best care at the best time.
   - Improve trust – Patients can have access to information, credentials, and studies easily.
   - Opportunities to link with current resources already in place (811 Healthline, 211 United Way).
   - Easy access for patients to search service directories, find community-based organizations and affiliates, support groups, and facility locations.
   - Link patients to education opportunities, support groups, holistic programs, etc.
4. **Prevention**
   - Apps can encourage patients to manage their health proactively
   - More likely to stay connected with their healthcare team and follow their wellness regime through an improved wellness experience
   - Could foster exercise and healthy living by tracking physical activity
   - Prevention education and tips could be promoted
   - Patients can track doctor visits, tests, etc. to maintain their health journal
   - Ability to partner with reward programs (i.e. [https://www.carrotrewards.ca/home/](https://www.carrotrewards.ca/home/)) that are already adopted by provincial governments across Canada

5. **Improved financial and operations efficiency**
   - Reduce readmission or connect with cheaper options for healthcare outside of the higher cost acute settings.
   - This can be done through:
     - Providing discharge summaries directly to patients (brochures, videos, etc.)
     - Care teams can send targeted messages including appointment reminders, medication logs,
     - Provide easy access to healthcare information and resources
     - Cost-effective solutions for healthcare delivery with rural or remote patients or patients that require frequent follow-up care or monitoring (chronic diseases, etc.).
     - Cheaper than mailing out paper surveys and utilizing resources to tabulate data

6. **Functionality could be introduced in multi-phases/stages based on priorities and can evolve as needed**
   - Apps can be built to function across multiple platforms in a reasonably cost-effective manner
   - Continue to cultivate more patient-focused care
   - Possibility to create clinical efficiencies
   - Gain greater insight into the social, economic and environmental factors that influence patient health to be used and shared across ministries

7. **Boosting the new SHA brand image and reputation**
   - Would show the general public that the SHA is serious about transparency and inclusion.
   - Would create more trust in Saskatchewan health care as the populations would be more actively engaged, and increase the visibility of the SHA in peoples every day lives.
Challenges of Implementation of an “SHA Healthcare Dashboard”

- The initial cost may be prohibitive, but not unattainable if current portals are researched and can be adapted for SHA needs.
- Patient SHA employee awareness, comprehension, and adoption
- Education around portal applications.
- There will be a need for developing a framework for evaluating the patient engagement, quality, and safety of Mobile Health Applications.
- There are still limited options for tools to assess the quality of mobile health apps.

Conclusion

To the general public, all members of a healthcare team are leaders and are often sought out by friends, family and even strangers for advice on navigating the health care system. Training should be available and encouraged to all healthcare workers in the province with focus on patient navigation, online resources, and patient advocacy. Any health care worker should be able to at least point a member from the public in the direction of the resources they need. This would help bolster confidence in the general public’s confidence in the health care system, and help empower patients own ability to be an advocate and leader for their own healthcare journey.

Currently, we are within a health care system that is facing increasing financial challenges in meeting the demands for health care in this province. The role of active leaders will continue to be critical in achieving positive financial and clinical outcomes, and that will empower the patient voice for those we care for. It is essential that with the Saskatchewan Health Authority’s new strategic direction, we aim to make significant contributions to invest in leaders who strive to truly transform the health system to one that never loses sight of the patient voice. We must focus on a health care system that will increase transparency for the patient, and invest in resources that will ensure that we are responsive to the needs of all patients as they navigate through their health care journey. We feel that the leadership capabilities required to adopt this culture lies in each and every one of us involved in the delivery of health services. In continuing to engage patients, and improving transparency and communication, we will only continue to build these vital collaborative relationships and make the Saskatchewan Health Authority a place where the patient truly feels empowered and has a voice.
Appendix A

Healthcare in Saskatchewan – Macro External Environmental Scan

The PEST (Political, Economic, Social, and Technological) Analysis is a framework used to scan the Saskatchewan healthcare external macro environment. The goal of completing a macro environment analysis is to answer the following questions. What environmental factors will affect Saskatchewan Healthcare? What is the likely cumulative impact of all of the things that may change the healthcare state?

Political
- In early 2018, Scott Moe was elected to replace Brad Wall as leader of the Saskatchewan Party — and 15th premier of the province.
- Marijuana legalization is expected in summer 2018. Marijuana revenue or expenses are expected to be left out of the upcoming budget and due to this uncertainty, we are uncertain as to what regulations will look like when it’s legalized.

Economic
- Saskatchewan’s economy is recovering from a sharp downturn in its energy sector and is projected to lead the country in GDP growth in 2018 and 2019. (RBC)
- Based on the survey real GDP growth is forecasted at 2.1 percent for 2018 after an estimated 2.0 percent rebound last year, and an increase of 1.9 percent for 2019. This increase will bump up Saskatchewan to the fourth position on the provincial economic growth leader-board for 2018, and second most robust growth next year. This is a significant improvement from last year where Saskatchewan was ranked seventh. (SREDA)
- Saskatchewan is invested $5.2 billion in 2017-18 in core health services and infrastructure to meet the healthcare needs of Saskatchewan people. The 2017-18 Health budget increased $38.6 million (0.7 percent) from 2016-17 and more than 51 percent since 2007.

Social
- The population is growing fuelled by international immigration. The 2017 population was measured at 1,196,510 (594,556 women and 601,954 men). Over the past year, 16,047 people moved to the province, representing a growth rate of 1.4 percent.
- The Saskatchewan Health Authority is the second largest health system in the country.
- Health coverage in the province is split amongst the following community types: cities (62%), towns (16%), rural municipalities (8%), villages (8%), reserves (6%).
- 13% of the province at First Nations (Indigenous), with 50% living on reserves
- Saskatoon and Regina Qu’Appelle serve 56% of the residents in the province.
- The highest age cohort of the population is between 24-34 years of age; 33.4% of the population is over the age of 50.

Technology
- Saskatchewan’s healthcare providers have been successfully incorporating the use of technology for various health services including applications of electronic and digital technology includes robotic technology, internet, tablets, cell phones with disease-specific apps, telehealth, remote ultrasound and liver scans
Appendix B – Populations Served by Former Health Regions & Age Cohorts

<table>
<thead>
<tr>
<th>Former Health Region</th>
<th>Population Served</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saskatoon</td>
<td>369,878</td>
<td>31%</td>
</tr>
<tr>
<td>Regina Qu’Appelle</td>
<td>304,684</td>
<td>25%</td>
</tr>
<tr>
<td>Prairie North</td>
<td>84,808</td>
<td>7%</td>
</tr>
<tr>
<td>Prince Albert Parkland</td>
<td>83,127</td>
<td>7%</td>
</tr>
<tr>
<td>Sun Country</td>
<td>60,479</td>
<td>5%</td>
</tr>
<tr>
<td>Sunrise</td>
<td>59,768</td>
<td>5%</td>
</tr>
<tr>
<td>Five Hills</td>
<td>57,353</td>
<td>5%</td>
</tr>
<tr>
<td>Heartland</td>
<td>46,276</td>
<td>4%</td>
</tr>
<tr>
<td>Cypress</td>
<td>46,079</td>
<td>4%</td>
</tr>
<tr>
<td>Kelsey Trail</td>
<td>43,145</td>
<td>4%</td>
</tr>
<tr>
<td>Mamawetan Churchill River</td>
<td>25,270</td>
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</tr>
<tr>
<td>Keewatin Yatthé</td>
<td>12,471</td>
<td>1%</td>
</tr>
<tr>
<td>Athabasca Health Authority</td>
<td>2,606</td>
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<tr>
<td>Out Of Province</td>
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<td>0%</td>
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Saskatchewan Health Authority - By Age Cohorts

<table>
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<tr>
<th>Age Cohort</th>
<th>Population Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt; 1</td>
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</tr>
<tr>
<td>1 to 4</td>
<td>5.3%</td>
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</tr>
<tr>
<td>10 to 14</td>
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<tr>
<td>15 to 19</td>
<td>6.0%</td>
</tr>
<tr>
<td>20 to 24</td>
<td>6.6%</td>
</tr>
<tr>
<td>25 to 29</td>
<td>7.6%</td>
</tr>
<tr>
<td>30 to 34</td>
<td>7.6%</td>
</tr>
<tr>
<td>35 to 39</td>
<td>7.0%</td>
</tr>
<tr>
<td>40 to 44</td>
<td>6.2%</td>
</tr>
<tr>
<td>45 to 49</td>
<td>5.8%</td>
</tr>
<tr>
<td>50 to 54</td>
<td>6.4%</td>
</tr>
<tr>
<td>55 to 59</td>
<td>6.6%</td>
</tr>
<tr>
<td>60 to 64</td>
<td>6.0%</td>
</tr>
<tr>
<td>65 to 69</td>
<td>4.6%</td>
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<tr>
<td>70 to 74</td>
<td>3.4%</td>
</tr>
<tr>
<td>75 to 79</td>
<td>2.5%</td>
</tr>
<tr>
<td>80 to 84</td>
<td>1.9%</td>
</tr>
<tr>
<td>85 to 89</td>
<td>1.4%</td>
</tr>
<tr>
<td>90 to 94</td>
<td>0.7%</td>
</tr>
<tr>
<td>95+</td>
<td>0.3%</td>
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</table>

Data Source – eHealth  [https://www.ehealthsask.ca/health-data](https://www.ehealthsask.ca/health-data)
Appendix C

*These partners are Government of Saskatchewan, the University of Saskatchewan, the University of Regina, the Saskatchewan Health Quality Council, the Saskatchewan Health Research Foundation, Saskatchewan Polytechnic, Regina Qu’Appelle Health Region, Saskatoon Health Region, and eHealth Saskatchewan.

Source: [http://scpca.ca/scpor-governance/](http://scpca.ca/scpor-governance/)
Appendix D

Significant milestones in Saskatchewan’s PFCC journey

Source: https://hqc.sk.ca/what-we-do/engaging-patients-and-families-as-partners
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Through Their Eyes:
How Social Determinants Effect Access to Mental Health

Gregory R.A. Jessup, Carli F. Davidson, Pamela L. Schneider, Michelle D. Compagna

University Of Regina
Creating a SIHL project which explored a topic relevant to the Saskatchewan Ministry of Health 2017-2018 (SKMoH 17-18) plan and exercised our leadership skills seemed to be a daunting task at first. Through discussion, we quickly realized that although our backgrounds and experiences were all somewhat different, we all valued mental health care and had been touched by the effects of mental illness in some way. This fit into the SKMoH 17-18 strategy stating: “[r]esidents of Saskatchewan will have access to appropriate and coordinated mental health and addictions services that promote recovery to the greatest extent possible, improve mental health and well-being and ultimately enhance the overall health and vibrancy of our communities and our province” (p.7).

In order to gain more focus on the direction of our project, we reached out to staff at the Community Care Branch of the MoH, to discuss one resource in their strategy: Internet Cognitive Behavioural Therapy (I-CBT). I-CBT is a program run by the University of Regina Online Therapy Unit and is free for residents of Saskatchewan. For the past three years, the Ministry of Health has been providing some funding to the Online Therapy Unit to increase mental health resources for residents of Saskatchewan. According to statistics gathered, the number of individuals enrolling in I-CBT programs has been growing steadily from 2014-2015, 355 enrolled, to 2016-2017, 635 enrolled (Department of Psychology, University of Regina, 2017, p. 1). When inquiring about the increases in enrolment, the staff at the Community Care Branch mentioned that besides a few interviews regarding the program, there was no active advertisement for I-CBT. All of the enrolment had increased almost entirely due to
word-of-mouth. We wondered if the majority of enrolments were from university students and if enrolment would increase if the program was advertised. Was their experience positive or negative? What recommendations would they have for improving how mental health care was implemented? These thoughts were originally what lead us to our focus: access.

Our project is an assessment of how Saskatchewan residents with mental illness feel about their current ability to access health care. In addition to this, we were interested in determining which social determinants of health these residents felt played a large role in their journey and ability to access care. To accomplish this, we decided to use Photovoice as a method to gather information from the individuals most affected. In addition to the above goals, we wanted to empower our participants to tell their stories in a dignified way, and work with them to create recommendations to improve the health care they use. Going into this project, we hypothesized that there would be a low level of satisfaction with access to mental health care, and that education, income and social support networks would be crucial social determinants of health to this subject.

**What is Photovoice?**

Photovoice is a tool we used in this project to gather information from participants in the community. It is a way for the participants to express their feelings and thoughts through pictures. It is also useful to help them convey their message in an impactful way, and to help the audience feel and understand the participants experiences, through their eyes. Photovoice was used as a research tool to get a unique glimpse into the lives of the participants living with one or more mental health disorder.

The heart of photovoice is the intermingling of images and words, this blending of
images and words is not a new idea. In fact, humans have used different kinds of images and words to express what we need, what we fear, what we cherish, what we dream of and all sorts of other ideas, for as far back as we know. Photovoice is one recent example using this form of expression.

Photovoice was created in the early 1990’s by Caroline Wang and Mary Ann Burris. It is a participatory action research methodology where, “people can identify, represent, and enhance their community through a specific photographic technique” (Wang & Burris, 1997, p.369). It is a creative way for participants to document their concerns and promote change within their community. Photovoice breaks past language and traditional communication barriers that often prevent members of a group from expressing their concerns (Facilitator’s Toolkit for a Photovoice Project, p.3).

There are three set goals that are to be accomplished with the use of Photovoice. The first goal is to enable people to record and reflect their community’s strengths and problems. Secondly, it promotes dialogue about important issues through group discussion and photographs. Finally, it engages policymakers, showing them that what they think is important sometimes doesn’t match what people in the community think is important (All About Photovoice, p.1).

We hope that through the use of photovoice we will impact the audience in a way that will help promote change to better the accessibility of mental health within Saskatchewan.

Environmental Scan (Patient Findings)

S.F (Greg’s Patient Findings)

S.F is a twenty-six year old woman from Moose Jaw Saskatchewan with post-traumatic
stress disorder (PTSD) and anxiety disorder, which manifests itself in the form of panic attacks ranging from mild to severe. Roughly seven to eight percent of our entire population has PTSD, with higher incidences found in women (U.S Department of Veterans Affairs (VA), 2018). In November 2016, she had a nervous breakdown and had to move back in with her parents to recover. Without the understanding of what was happening to her, S.F went to her General Practitioner (GP) for support and to find treatment options. The family doctor was unable to provide any information regarding any social supports or options for therapy, but strongly recommended medication as a treatment method. This was not the type of support S.F was looking for, and chose to access the Employee and Family Assistance Program (EFAP) through her work benefits. Through this avenue, she was put in touch with a psychiatrist office. The first psychiatrist S.F worked with identified that her anxiety originated from a three year relationship that had ended in the past year with a physical altercation. S.F was afraid that her former partner was going to come back into her life and “get her”. Regarding Intimate Partner Violence (IPV), twenty seven percent of women have been harmed by sexual or physical violence. IPV leaves the victim at a higher predisposition to a number of different physical and mental chronic conditions (VA, 2018). Although this information was helpful, S.F felt that she did not click well with the psychiatrist and moved to a colleague in the same office. After a year and a half of searching for support, this psychiatrist was able to point S.F towards local support groups, such as a PTSD support group in Moose Jaw, that she began attending. Yoga was also recommended as a positive tool for relaxation and de-escalating. Since S.F has a medical background, she found it very helpful when the psychiatrist spoke about PTSD from a scientific standpoint and provided books about the subject. Studies on PTSD have found therapy
focusing on education and relaxation to be more effective than focusing on emotional
debriefing (Bisson, 2007, p.399-403). Currently, S.F attends therapy every four to six weeks
unless there has been more crisis than usual, goes to yoga four times per week and enjoys
reading about PTSD as a way to understand and conquer her illness.

When asked about her negative experiences accessing mental health resources, S.F
criticized her GP for “pushing pills to make [her] happy” and lacking knowledge regarding
mental and emotional supports in the city that she could access. The National Institute of
Health and Care Excellence (2005) explain that GPs should take responsibility for “initial
assessment and initial coordination of care”. Further, “[A]ssessment of PTSD sufferers should
be conducted by competent individuals and be comprehensive, including physical,
psychological and social needs and a risk assessment”. It is also recommended that patient
preference is a crucial component, and should be honoured among the treatments being
offered. S.F felt that her journey to find adequate support would have taken even longer than a
year and a half if she had not had EFAP as a benefit through her work. Although S.F has a
psychiatrist now, there is still difficulty accessing them because of their typical weekday work
hours. Taking sick time from work for appointments so frequently leaves her with little sick time
to use otherwise if she becomes physically ill. Secondly, she is required to make appointments
roughly a month in advance and feels that this does nothing to support her through her crisis
moments. She is able to call or instant message workers through EFAP, however they are
usually not professionals. S.F also struggles with explaining her story to a new individual over
the phone every time when she would prefer to speak to someone familiar with her. She
explains, “I call them in crisis when I go into a panic attack because I want them right here right
now. I want something to de-escalate [the situation] and I want to talk to them when it’s fresh”. Along with her negative experiences, S.F identifies that there have been many positive experiences with her access to mental healthcare as well. She greatly values her relationship with her psychiatrist and feels that she owes much to her for the improved mental condition she is currently in.

The social determinants of health that S.F identified as most critical to her ability to access mental health care were income/education, social support networks, coping skills and early childhood development. S.F’s education allowed her to be able to get a job that pays well and allows her to afford therapy, which costs $120 per session and yoga classes multiple times per week (S.F noted that her psychiatrists’ office will lower cost for patients once their benefits stop covering their sessions). Her job also allowed her access to EFAP, which aided in finding her all of the resources that she currently uses. Although S.F has a good job, she still experiences financial stress from paying for extra costs to keep her mentally well, and feels that she grieves the loss of what would be disposable income for a “normal person”. She feels fortunate that she only accesses therapy every four to six weeks while she is well and stated “for someone that needs to go weekly that [would] add up really fast”. Social support networks have been an important part of S.F’s journey both in a positive and negative way. She has experienced the stigmatizing reality of having a mental illness when coworkers would call her broken, ridicule her for wanting to access therapy and tell her that “you’re normal, therapy is for desperate losers”. S.F has heard multiple people say that PTSD is only for people who have had something extremely traumatic happen to them, such as war veterans. Studies that attempted to predict individuals who would develop PTSD after a traumatic event found that a
lack of social support following the trauma played a large part (Bisson, 2007, p.399-403). There have also been positive examples of social supports, such as close friends encouraging her to seek therapy and supporting her through many of her crisis moments. During her physical altercation with her ex-boyfriend, S.F’s dog attacked the man and protected her. Whenever S.F has anxiety or panic attacks, her dog will lay with her and put his head on her chest. She claims that this dog has saved her life more times than she can count. S.F identified that the coping skills that she has gained in the last year are extremely important in maintaining her mental health. Yoga has taught her breathing exercises and visualization techniques that allow her to de-escalate and centre herself. Her therapy sessions have taught her to identify potential triggers and remove them, or herself, from the situation. When speaking about early childhood development, S.F said she did not wish to go too far into the subject; however, she feels as though she had a lack of intimacy during childhood that may have contributed to her situation. Growing up, she felt that her mother rarely encouraged her, and her family never said “I love you” to each other or shared their feelings. During one example of S.F being bullied in elementary school, her mother said “Just hide your feelings and don’t let them know that it bugs you”. This lack of expressing emotions delayed her desire to acknowledge her illness and seek help, in her opinion. Regarding her abusive relationship, S.F explained, “with my mom, I never felt like I was good enough growing up. I went into a relationship knowing I wasn’t good enough for him; it was what I was used to”. When her father finally recommended therapy, her mother said that she was “fine” and “independent”.

Prior to her Photovoice journey, S.F said that her hopes for the future were, to need to access therapy less and instead be able to use the tools that she has learned to aid in her
moments of crisis. She wishes to laugh more and have fun, stating “I have a positive outlook because [my therapist] set me up to be that way”. S.F would like to use Photovoice to “help get rid of [the stigma of mental health], that broken feeling”. She feels that increasing the promotion of mental health resources would aid others greatly. She had great difficulty knowing where to start accessing resources and feels others likely have the same issue.

After concluding Photovoice, S.F said she had issues picking only ten pictures, as there had been so many taken. She also enjoyed the concept of having the individuals with the issue be able to convey their emotions and message. When comparing Photovoice to other studies that she has read, S.F said “charts and graphs don’t get into the depth behind the subject, but pictures can really show the emotion and perspective”. After one session of taking photos, S.F felt so emotionally drained that her family was able to identify that something was wrong and it took the rest of the day for her to get back to her normal. S.F said Photovoice “really opens you up to those intense feelings that you had [and] makes you face them again”. When asked again about possible recommendations for improvements on access to mental health resources, S.F stood firm on her opinion that the healthcare system needs to advertise the mental health supports that are already in place, because of her great difficulty finding the ones that worked for her.

**J.S, P.S, A.S (Pam’s Patient Findings)**

J.S, P.S and A.S have a story to tell. Their story is raw, intense and very real. The story doesn’t begin on June 9th, 2016 but this is the day major tragedy fell upon them and changed their lives forever. J.S and P.S’s son, A.S’s older brother, R.S, took his own life on June 9th of 2016 in his parent’s home at approximately 4:30pm. J.S and P.S were upstairs. J.S went
downstairs to get their son for supper. What he found was his son hanging from the duct in the ceiling from his brown leather belt, unconscious. J.S grabbed his son and tried to lift him up to loosen the belt, screaming for his wife to help. P.S, who had recently undergone surgery to both her feet, tried her best to get to them quickly, she called 911. J.S then performed CPR on his first born child until the paramedics arrived. Unable to bring their son back to this world, he was pronounced dead on the scene and an RCMP officer drove J.S over to their daughter’s home to deliver the unfortunate news. A.S, at home with her young daughter, was portioning out ground beef for meal prepping that week, completely unaware of the loss that was about to be explained to her. When her dad came to her door with the police officer, she knew the news was not good. She looked at her father and whimpered the name of her husband, whom she recently separated from, assuming something had happened to him. J.S shook his head and said “it’s your brother, he’s gone”. A.S instantly collapsed in overwhelming grief while J.S picked up his granddaughter, a toddler at the time, who was crying and scared. Soon after, they drove over to A.S’s parents place where they said their final goodbyes to their beloved son/brother, a forever goodbye that came much too soon. R.S not only left behind loving parents and a younger sister very dear to his heart, he also left behind a son and a daughter and many close friends and family.

R.S, who was 36 years old when he passed away, suffered from a deep depression. It was a series of events in his life that took him to such a dark place that he believed the world was better off without him. R.S and his wife split up, leaving him no option but to move back in with his parents. He lost his family and his home. Soon after, he lost his job and his passion
for being a welder. Feeling there was no other option, he decided to take his own life, in his old bedroom in the home he grew up in, while his parents were upstairs. That is how sick he was. “Suicide accounts for 24% of all deaths among 15-24 year olds and 16% among 25-44 year olds. Suicide is one of the leading causes of death in both men and women from adolescence to middle age” (Canadian Mental Health Association, 2013). R.S’s family feels these numbers are only going to increase and that action towards prevention and early intervention need to happen now. They don’t want anyone to go through the pain and loss they are suffering through and will suffer through for the rest of their lives.

Prior to taking his own life, there were a few instances when R.S felt he needed help for his depression. The first occasion was after R.S had visited the marital home to talk with his wife whom he was separated from. They got into an altercation and his wife’s mother called J.S to come get R.S as he was refusing to leave. J.S came and picked R.S up and as they parked in front of J.S’s home the police showed up. R.S’s wife had called the police before he left so they came to talk to R.S and assess the situation. At this time, R.S decided he wanted to go to emergency to seek medical attention. The police drove R.S to emergency where he waited for 2 hours to be seen by a doctor for 10 minutes. In that 10 minutes, the doctor wrote a prescription and a referral for him to attend a counselling session at the addictions centre, in a weeks’ time. The doctor also advised R.S to take 6 weeks off of work to try to get better. R.S was asked if he wanted to be admitted and he said “no” and was then sent home. This occurred about 2 months after R.S and his wife split up and 5 months before he took his own life. R.S did attend the follow-up appointment booked for him at the addictions centre, but never got his prescription filled for the antidepressants prescribed. He did take the medications
that were given to him in emergency, but once they ran out he stopped taking them.

Then, again about 2 months after his first ER visit, R.S decided to admit himself into the psych ward for 3 days. He showed up to his parents’ home the day he left the hospital and told them where he was, as they had no clue and were worried. When they asked him questions he stated he didn’t want to talk about it, all he told them was that he left against medical advice. The family also remembers that R.S had attended approximately 3 counselling sessions, they state that R.S and his counsellor didn’t seem to have a good connection and that R.S was not too enthused with the sessions. P.S believes in order for counselling to be successful there needs to be a connection between counsellor and client, trust needs to be built and the client needs to feel comfortable enough to tell the truth, as most people will lie. P.S states she knows this to be true because she has lied to counsellors in the past, and knows that they cannot appropriately help clients unless they know the whole truth.

R.S’s family believes that R.S did not receive the care required for a suicidal patient. J.S believes, “there is something wrong with the system, we need more funding for more treatment – more doctors, more counselling, more programs, better treatment”. J.S states “since my son’s death, I am doing everything like I used to do before but it doesn’t feel the same. This can make things difficult, at times, to keep doing everything as before because once I start to enjoy something I begin to feel guilt. So, I am working on getting past this and understanding that this is something that may carry on for the rest of my life. I don’t believe there is a cure for what we are going through, just that we have to get through it.”

J.S and P.S are fortunate enough to have family services provided to them through J.S’s
work. J.S is a long time employee of the City of Regina and through the city they have the option to attend monthly counselling sessions that are completely covered. This is a major benefit as one session is approximately $150/hour. J.S states “there is no cure for what we are going through, but to talk to a counsellor is helpful because it gives us another perspective from an outside person, (not in our circle) who can give some advice and guidance and to feel safe. Talking about anything you want is also helpful.” J.S mentions that if these counselling sessions were not paid for through work, it would be a struggle financially to make it work. He asks “how can anyone out there with a problem afford to talk to anyone on a regular basis when there are no funds available to them?” They believe counselling twice a week is required for crisis situations and that money is an issue in accessing care for mental health issues.

P.S discusses how she suffers from anxiety resulting from PTSD from a car accident 30 years ago. She stated it took about 20 years to resolve the PTSD/anxiety and that the recent suicide of her 36 year old son has caused her PTSD symptoms to return, along with stress and anxiety. P.S has learned throughout the many years struggling with mental illness, that to remain stable she has to put in hard work and determination. After her car accident she turned to drinking, she lied to her psychiatrist about her drinking and was prescribed prescription painkillers, Valium and antidepressants. These pills would become her way of coping through her trauma, which later turned into addiction. P.S, luckily, had a strong support system and was able to go through 2 months of rehabilitation while her loving husband stayed home and cared for their 2 young children on his own. An important fact to mention, is that the 2 months of detoxification for P.S were completely free of charge and covered by her health card, this was in 1985. P.S mentions how difficult being away from her family was and how those 2
months went by so slow. She states that without her husband 100% supporting her through that time in her life, there is no way she would have made it through. To keep from relapsing, P.S knows what she has to do. She states “once my husband retires and we lose access to the family treatment centre, I will still go to counselling and I will figure out finances because I will have to in order to remain healthy and strong”. She states “it will be a struggle because I don’t have a pension, but we will have to figure it out”. She knows through past experiences that she has to continue with therapy, as it is ongoing for the rest of your life. She states she currently has her mental health under control, but she could easily get back to where she was. She knows the healthy things she has to do to remain strong, but mentions again how it is an ongoing thing all the time. P.S mentions that she could easily be on high blood pressure pills, pain pills, sleeping pills and antidepressants, if she asked her doctor, but she refuses to do so. She is taking a healthy approach and feels diet, counselling and exercise are far more therapeutic then prescription medications. Studies have shown that people who eat fresh vegetables, fruits, unprocessed grains, fish and seafood have a 25%-35% lower risk of depression, compared to people who eat diets that include processed and refined foods and sugars (Harvard Health Publishing, 2015). The family all believe that eating a healthy diet and regular exercise are two crucial factors for mental health stability, for all people in the world.

J.S believes people who are dealing with mental illness need to be told to be physical, because they won’t do it on their own. He mentions that through his work plan he also gets a discount for fitness facilities in the city. He states that many large companies have fitness centres right in their office buildings, they are aware that when staff are active on their breaks they are more productive when returning to work. He states how people dealing with
depression are not aware of the benefits of being active and that they need someone to tell them and guide them. “There is now increasing recognition of exercise as a treatment option for depression. Not only can it help reduce depressive symptoms, but it can also help medications work better. In fact, studies now suggest the treatment of depression with exercise is on par with cognitive therapy and antidepressant medications in terms of the overall effect!” (Your Mental Health Matters, 2016).

J.S believes if a person is depressed related to the environment they are living in, then they shouldn’t be sent back to that environment. He believes that was a major cause in his son’s depression and that he never got the chance to change his environment. He states to appropriately diagnose depression the root of the problem must be recognized, such as loss of a job, broken marriage, loss of family etc. Providing coping strategies to people to deal with all those issues is key, but if you do not have a “dime in your pocket, who are you going to talk to?” He believes that these people then turn to “booze, dope and the streets” as coping mechanisms, as they cannot afford to access the appropriate help they need.

A.S speaks to this as well, and states that a holistic approach is more effective in treating mental illness, such as diet, exercise, counselling, and the use of medications can pull people out of a rough patch, but as a temporary solution. “How many doctors just push pills and let the patients walk out the door. What about the other coping mechanisms and strategies that these people will need to overcome their illness? There is rarely discussion in a doctor’s office outside of the medications prescribed and often these medications take weeks to start taking effect.”

The family also discusses their hopes for the future of mental health and they have a
strong belief that early intervention is key. Imagine teaching children throughout kindergarten to grade 12 how to cope with trauma, and that it is okay to talk about your feelings? According to the Mental Health Commissions of Canada, mental illness is increasingly threatening the lives of our children; with Canada’s youth suicide rate the third highest in the industrialized world. If we could teach children early on how to cope we could maybe decrease that number.

Alongside early intervention, they also believe that a mental health clinic that could serve as a “one stop shop” would be highly beneficial as well. A place that not only had doctors and therapists but dieticians, exercise therapists, support groups and different levels of care for patients with varying mental illnesses.

The social determinants of health that are most prevalent, regarding access to mental health care, include income and funding, social support networks, employment and coping skills. As discussed previously, the family often mentions the importance of diet and exercise as a coping skill for mental illness, they mention benefits through employment making access affordable and that having a strong support system is key in overcoming mental illness/addictions.

Although the loss of R.S is overwhelmingly tragic and threw a massive curve ball into their future plans as a family, they do hope their experience and their story can help others. P.S’s hope for this project is that it will help shed a new light on what exactly depression and mental illness is, and how people are going through it. There is more people than we know experiencing some form of mental illness who aren’t talking about it and we need people to be ok with saying that they need help and to be open about what they are going through so more people can get the help they need.
J.S believes this project is another avenue to get the message out because he believes depression is a silent killer. The less you talk about it, the less people know about it the more people want to cover it up. It is a silent killer, and it is devastating. When it happened to them he saw fear in the eyes of people he knew, he knew they realized that something like this could just as easily happen to them.

A.S discusses the use of Photovoice in the project and believes that “because people do not know what other people feel like, pictures could help explain those feelings which can help others relate to the feeling through the picture.” She believes it could help people, who have no idea what depression is, gain an understanding of what someone is going through by looking at the picture. “In any given year, 1 in 5 people in Canada will personally experience a mental health problem or illness.” (Mental Health Commission of Canada, 2013). No matter who you present to, the possibility of the audience members knowing someone who suffers from mental illness, or has a mental illness themselves, is very high. Photovoice is another avenue – people are visual and this is a visual thing and it is very impactful.”

In conclusion to this experience for the family, they state that although it has been very emotional and heightened, they believe any input they have towards mental health awareness and treatment is critical, as it could help others. They mention how important it is for people to share their stories and not be afraid to talk about it, spreading awareness is a positive step to implement change. They also recommend more funding towards mental health, as they believe Saskatchewan’s suicide statistics are over the top and has the poorest health care for mental health. A change needs to happen so people can be cared for appropriately, only then will we see more success stories, along with a decrease in statistics around suicide.
C (Carli’s Patient Findings)

C is 46 years old, holds a Master’s degree in sociology from the U of R and is currently the executive director of an outreach program in Regina. She has been diagnosed with an eating disorder, depression and anxiety, PTSD and an addiction to alcohol. She states that she first developed symptoms of mental illness at the age of 8, when she recalls experiencing suicidal thoughts. She started self-harming at the age of 13 in the form of cutting, resulting in requiring stitches on multiple occasions. She was first referred to Child and Youth services of Regina at age 12, and accessed their programs and services for the following 10 years- with little to no improvement in managing her mental illness. During her youth, C describes phases of severe depression and rage, alternated with phases of emotional numbness. She was medicated with tranquilizers that she would pretend to take and hide under her bed, since taking them would "knock her out for days". During her youth she also struggled with restriction and binge eating cycles.

As an indigenous woman, C states that the number one social determinant that she believes affects access to proper mental health care is race. She is Inuit, and was adopted into a white, middle-class family when she was quite young. While explaining her childhood, she mentions an abusive relationship with her adoptive father and suffering sexual abuse as a child. She moved out at 14 and entered into what would become an emotionally, physically, mentally and sexually abusive relationship with her now ex-husband for the next number of years. Despite becoming pregnant at 15, she finished high school with merits and had a second child after graduation.

C recalls a breaking point at the age of 20, after experiencing years of abuse in her
relationship (including black eyes and cracked ribs on multiple occasions), she developed a sense of overwhelming isolation and hopelessness for the future for herself and her children. After overdosing in a suicide attempt, she was referred to Regina Mental Health, where she worked with Dr. Colin Smith. C credits Dr. Smith with helping change her life, she expressed that he was the first mental health professional she encountered who legitimized and validated her feelings. With his support and being prescribed correct medications, her mental health changed for the better.

C started university and claims that, on some levels, academia saved her. C conveys she became obsessed with her studies and achieving something and that, in part, contributed to a relapse into her eating disorder. Her restrictive diet led to over 100 lbs of weight loss and although she was working with a team of a psychiatrist, psychologist and nutritionist, she states her eating disorder showed little improvement for a long time. At one point, she recalls a doctor telling her he was concerned for her life after they were unable to put an IV in her collapsed veins. She slowly was able to retain some control over her diet and began to eat again, at which point she became pregnant with her third child. By this time, she was an honours student, active in the academic and social life of the university and described herself as a "workaholic". She was often assisting more than one class, taking a full class load, and assuming the bulk of household responsibilities, with little support from her then husband. Eventually she divorced her husband, while pregnant with her fourth child, and started her master’s program. She continued to struggle with the results of the environment her ex husband created for her and her children. Her children were raised in a precarious environment, affected by poverty, negative influences of living in "the hood" and violence and
abuse by her ex-husband.

Her oldest daughter began to exhibit signs of behaviour problems early on in her childhood, including compulsiveness and periods of being extremely "hyper." Despite being referred through Child and Youth services, and working closely with her schools as she got older, C states the majority of the programs focused on parenting skills instead of the underlying mental health issues. C suspects her daughter had undiagnosed ADHD and states she later received a diagnosis of oppositional defiant disorder. Her oldest son also started exhibiting signs of dangerous addiction and mental health issues. C was advised by police and family members that they should be put in care to protect themselves, and their family, especially C's younger children. This was a particularly difficult decision for C as she is adopted and has existential issues with this separation. Her 2 older children were in and out of social services for a couple of years, while C attempted various means to get them help. She tried working with social services, a lawyer and the mobile crisis unit to access them appropriate care. Eventually, they returned home with unaddressed mental health issues that continue to be detrimental to their own and C's lives until this day.

Her oldest daughter has struggled with addiction throughout her life and had three children by age 24. She eventually attended university, where she was very successful, she was a student rep for First Nations students, and came within weeks of graduating a double majors degree before "crashing." She became addicted to meth and adopted a high risk lifestyle, including homelessness and prostitution. C states she no longer has custody of her children and has had little to no contact with her for the past two years. This is an ongoing struggle for C as she is mourning the loss of a daughter compounded with managing her own mental health.
C states her oldest son also currently suffers from severe addiction and helplessness that is associated with his addiction and mental health issues. He has moved in and out multiple times and has been trying to self-medicate with substances throughout the years. C describes her son as high functioning despite being in and out of the psych ward and in and out of jail. He has consistently been in school and employed, succeeding at both. C suspects he has a multitude of undiagnosed, untreated mental health conditions and describes behaviours of very productive mania, marked by accomplishments, but unrealistic expectations of success.

With C's extensive experience in multiple areas of the mental health care, in Regina, as a patient as well as a mother, she describes it as the "most oppressive and dehumanizing system that exists." She communicates that the majority of her experiences as "overwhelmingly negative" and her opinion is that race is the primary determinant in the level of care that is received, specifically by indigenous people. She used a few examples to support her viewpoint, describing a situation where she went for an X-ray and received a "cold" attitude from the receptionist, after she witnessed the previous two patients being laughed and conversed with. When asked to use the washrooms, she was told they were in a different department. She also experienced assumptions made about her children having the same father while receiving treatment when one of her children was ill. She mentions multiple times the detriment of the excessive wait times to access mental health services in Regina. C has also accessed care through private care therapists with mixed success. She expresses that many private therapists are not indigenous and have a hard time understanding the traumas and backgrounds of Indigenous patients. She does not discount their professional competence, just their effectiveness in being able to connect. C also explained that, intermittently, her social support
networks have been a social determinant that affected her access to care throughout her life. She credits being raised in a household that valued education, and having a network of extended family and friends, who showcased positive behaviour, helped her to be successful. Nevertheless, she explains that her social support networks were negative at times as well and the childhood abuse she experienced was debilitating.

C affirms a strong opinion that racial stereotyping and discrimination is at the forefront of inadequate mental health access. "I believe there is a lot of stigma within the various systems themselves, even more so than what one encounters outside of those systems. The stigma I have encountered is racial stereotyping and discrimination – a loss of credibility compounded by the stigma of mental illness. Our entire system is permeated with racism – health, social services, education, justice and corrections. While some people think of overt racism as a problem, which it is, implicit racism or microaggressions/microinequities are continuous. While the health region has used cross cultural means with which to address this – cultural differences are not at the root of the problem – I am no ‘culturally’ different than most people working in the system. It is racism, which is not about fear or difference, but about privilege and until you begin to work on eradicating these issues within our systems by having the people/systems deconstruct their own belief systems, there will be no change."

Despite this, C expresses hope for the future and is eager to be an advocate for change within the mental health system, she stresses that it is vital for "services to meet client need in order to be effective...their needs and ideas must shape the services." She agreed that Photovoice is an effective tool to collect information stating "studies should be done in various formats to accommodate the differences among the clients that are being served."
V.H (Michelle’s Patient Findings)

V.H is a 35 year old female who is from Regina, Saskatchewan. V.H suffers from depression, which she was diagnosed with at the age of 15. According to Statistic Canada’s 2012 Canadian Community Health Survey on Mental Health, 5.4% of the Canadian population 15 years and older reported symptoms that met the criteria for a mood disorder, including 4.7% for major depression. Her mother, who was a registered nurse, first noticed signs of severe mood swings and a withdrawal from sports and after school activities. Her General Practitioner prescribed her antidepressant medications for her symptoms, and after approximately one months’ time, V.H stopped taking them due to the fact she had not noticed a change in how she was feeling.

Fast forward 15 years later, V.H realized the importance of taking her depression seriously and decided to reach out to the Adult Mental Health Clinic in Regina. The final push that gave her motivation to look for help was that her emotional state was very low. She was crying weekly and was unable to get excited about anything. The Adult Mental Health Clinic is a clinic that provides a wide range of community based services for individuals who have significant problems and, thankfully, is free of charge. V.H speaks with a mental health worker on a regular basis and is currently taking antidepressants as prescribed. She has learnt the importance of self-care, loving herself and not feeling guilty asking for what she needs through her mental health worker. V.H feels that since she committed herself to the above regime she has seen her mental health significantly improve.

V.S believes that because her mother had a health background and was able to
recognize her symptoms at a young age, this helped her to not be ashamed of her
diagnosis. She also feels that the journey with depression is easier as a woman because
depression is more acceptable towards women than men. Studies have consistently
documented higher rates in depression among women than men; A ratio average of 2:1 as
stated by the Canadian Mental Health Association (n.d). V.H also mentions that
being open and unashamed at work has helped reduce the stigma, but believes more could and
should be done. She realized the importance of putting herself first and knows when she needs
to take time off work to attend mental health appointments, she is open with her supervisors in
requesting time off for a mental health day as well. On top of that, she sees her doctor every
two months to make sure she stays on track in keeping herself mentally strong.

According to The Canadian Mental Health Association, 500,000 employees miss work
per week due to mental health which costs the government ten billion dollars per year. In
addition, in any given year only 23% of people say they would talk to their employees about
their condition. Initiatives like the “Not Myself Campaign” are essential for reducing the mental
health stigma in the workplace. When asked about her negative experiences accessing mental
health, V.H did state wait times were very long, often taking several months to see a
professional for symptoms that usually require immediate attention. Another concern V.H has
is that she came to know her first mental health worker was laid off and she realized that
vacant positions were not being filled. Despite this concern, she states that the quality of
professionals she has seen throughout her journey have been amazing, and that they were all
well educated and full of resources.

The social determinants of health that V.H identified throughout this project were
education, employment/working conditions, gender and social support networks. As previously mentioned, she grew up with a mother who was a registered nurse and who identified her symptoms early on. Despite her early diagnosis, it took V.H a long time to seek out the appropriate treatment. In the beginning she closed herself off from her family and social life, this isolation, in turn, only added to her depression. As she matured and had more knowledge around her diagnosis she realized the importance of reaching out. A major support throughout her journey is the fact that her place of employment has been and continues to be extremely understanding. They respect and support the time she needs off which is a huge relief to her. V.H understands that this is not a reality for all employees as many workplaces are not as understanding as hers. She also believes being a female and having depression is more socially acceptable compared to men who suffer from depression. She feels if she was a man, the expectation to suppress feelings could lead to alcoholism or drug dependency.

Prior to her Photovoice project, V.H hoped others would be encouraged to seek the help they need, and those in charge of the designation of funds will take value in taking care of the mind, just as much as the rest of the body. She wants the stigma to end and dreams of a time where we can all live a happy, fulfilling life, despite our mental health issues.

After finishing her Photovoice project, she had time to reflect on her mental health journey. It made her open up and think about things in a different way. She states it would be especially helpful to individuals who are just starting their journey to mental wellness.

**Summary of Patient Findings / Results**

There are many commonalities in regards to the social determinants of health with our participants and how it affected their access to mental health resources. They include
income/education, social support networks, healthy childhood development and coping skills.

Many important determinants were seen in both a negative and positive light. For example, at times in our participant’s life, lack of social support networks has isolated each of them in their own ways. The lack of understanding and stigma around mental health left room for judgement about what they are dealing with. Yet at the same time, many spoke about the overwhelming sense of support from a family member, friend or co-worker that carried them through to keep fighting against their mental health disease. Income/education also played a key role in awareness and accessibility to helpful resources. According to Mikkonen and Raphael (2010), Income is perhaps the most important social determinant of health, as it shapes psychological functioning. In addition, without work benefits, regular counselling would have not been possible for two of our participants. Once resources are accessed, our participants have learnt healthy coping skills to confront their individual struggles. Childhood development has also played both a negative and positive role in our candidates’ lives. For instance, a lack of intimacy and abuse has made it difficult to trust others to receive the guidance and help so desperately needed for two of our participants. According to the Federal/Provincial/Territorial Advisory of Population Health, There is a strong evidence that early childhood experiences influence coping skills, resistance to mental health problems and overall health and well-being for the rest of one’s life.

Strategies and Recommendations

The opinions and experiences exhibited by our Photovoice participants showcased a clear pattern, highlighting specific factions of mental health care and access that are vastly ineffective. Based on the information that was gathered and the trends that were exposed, we
have composed recommendations for improvements to mental health care and access in Saskatchewan.

A common theme that resonated in each participant’s story seemed to be the importance of social support networks. Another common theme relates early childhood environments and the implications of childhood trauma on future mental health. The significance of early intervention for at risk children and youth is highlighted as a preventative measure. It would eliminate the need for extensive mental health care later on in life, in turn, saving lives as well as health care dollars. It is apparent that mental health awareness needs to be incorporated into the school system, along with development of techniques for coping with anxiety/stress and trauma at an early age. There is also a need to identify children, as early as possible, who are at risk to develop mental health conditions, whether it be from trauma or a genetically increased probability. This identification and screening is most effectively carried out by family or close friends of the individual. This brings us to our next recommendation that emphasizes the importance of social support networks. Not only is this vital for mental health in childhood but throughout an individual’s entire life. Therefore, a focus on education and implementation of healthy behaviour and relationships, for support networks, is crucial.

Our frontline care workers also need more education and awareness related to dealing with mental health conditions. Often, these are the first health professionals that come into contact with patients and the advice and support they offer are integral to the success of treatment. General practitioners need to be aware of all the non-prescription resources available to their patients so they can advise their patient a treatment plan that will be most
effective for them. An example demonstrated from one of our participants is that her general practitioner exclusively offered medication and didn’t offer any other programs or therapies that could benefit her. She later learned about a PTSD support group that has been beneficial to her recovery, and could have been a potential resource her practitioner could have offered her.

A widely expressed, extensively acknowledged impairment of the system, by our participants, is the wait times for services and professionals. As the wait times of services and programs differ depending on many variables of an individual’s condition, it is difficult for us to focus on an area of service where wait times can be reduced. This was a point that was remarkably stressed by our participants, so we are hoping to increase the awareness of this detriment. Any options that can be explored, whether that be shifts in financial or resource focus, that would improve wait times, would greatly benefit mental health care for our province as a whole.

Lastly, through this project, we have experienced the impact and validity of gathering information through Photovoice projects. We believe this practice can be implemented in many areas of mental health and addictions care for accurate representation of the effectiveness of the system. We have suggested the implementation of Photovoice as a tool for professionals and practitioners to triage their patients. As the images gathered are a raw and emotional representation of the patients’ state of mental health at a specific time, we believe they can convey the urgency of their need for medical attention. Often, during a time of crisis, it is difficult to articulate or emphasize the seriousness of the state of the patients’ mental health. We propose that professionals use Photovoice as a triaging tool to gauge which patients need attention and in what order. We hope that this would help prioritize patients’ needs and avoid
crisis situations involving emergency department visits. As a whole, this would decompress the need for emergency response resources, as well as the frequency/intensity of therapy visits (compared to the visits needed if left to escalate to a crisis.)

**What We Have Learned as Leaders**

Throughout this project we have learnt the importance of adapting as a group and using each other’s strengths to get the job done. It has proven very helpful to be aware of our color personalities, which we learned during the first week of the course. For example, knowing when to bring out your less dominant colors to ensure everyone stays on task has been beneficial to the team. Every group member on this team has blue as their strongest personality which could have caused some issues in making final decisions and delegating tasks. Fortunately, we were able to work together well by following the charter and delegating a group leader who has red as their second strongest color. Our group leader learnt when it was vital to bring out the red to keep us on track.

Another important method we incorporated into our meetings was to set aside time to talk on a personal level, which helped us to build relationships with one another and grow as a team. We also learnt how important it is for all health care professionals to be more aware of their "first contact" with patients, especially patients of different races and minorities as these patients may have sensitivities. Greeting patients with a welcoming smile goes a long way and may make or break that patients experience in that appointment or meeting. After hearing some of our participant’s stories, we were amazed at how a cold shoulder or a seemingly judgemental glance can lead to altered perceptions of our entire healthcare system. This had us reminiscing about systems theory, which we learned at our week retreat with SIHL, and how
important is it to make a positive first impression with clients, no matter if you are on a macro level, a micro level or anywhere in-between. A negative experience can very easily carry over until the entire system is painted with the same brush.

The third point we discussed included leadership within our careers. How we as leaders need to work on being supportive to staff when they are going through traumatic personal events that may hinder their ability to do their job to their full potential. How does a leader balance being supportive and ensuring the organization will still run effectively? How does a leader "triage" all the staffs problems and know which should be granted time off and which shouldn't? We all know that “life” happens to everyone, so how does a leader time manage being a support network for their staff as well as complete all other important job duties? This project has brought up these questions as it has increased our awareness on the struggles that many people have with their mental health, we are less "jaded" or "naive" then we were prior to working on this project.

Our overall experience working as a team has been a positive one and we all have built positive relationships with one another. We helped each other through some tough times and kept great communication. We built trust and managed to make this project a lot of fun, even though our topic is a difficult one to work through. We have enhanced our views on mental health and we all expressed passion in telling the story of our participants. Although this project was a lot of work it was completely worth it, and we all agree that we have grown as leaders by working together on our presentation.
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