

PATIENT EXPERIENCE AWARDS SUBMISSION EXEMPLARS

The following four submissions have been shared with the permission of the applicants. They were submitted in different years, during which the criteria were the same as the current criteria, but the prompting questions describing each element were different.

Patient statements are unchanged from the originals, except where indicated to ensure privacy.

1. Pediatric Interdisciplinary Neurodevelopmental Clinic (PINC) Glenrose Rehabilitation Hospital (2026)

[Names were redacted and details in the family statements of support were condensed or paraphrased to protect the families' privacy.]

The Opportunity for Change or Improvement

Created in the late 1990s, the Pediatric Fetal Alcohol Spectrum Disorder (FASD) Clinic at the Glenrose Rehabilitation Hospital was aimed to support the assessment and diagnosis of children with FASD. Since then, scientific knowledge has evolved to help us understand that beyond alcohol exposure during pregnancy, there are many other factors that impact a child's development such as genetics, trauma, prematurity, exposure to other drugs, co-existing health conditions and even social factors such as racism, and poverty.

Because of these changes, our FASD clinic has shifted its approach. By listening to patient and family stories, we have learned that families are seeking more individualized care rooted in an understanding of their health framed in their diverse histories and contexts. Although our clinic continues to provide the FASD diagnosis, the focus of clinical assessment has shifted towards understanding the child's health and disability within each child's unique story and family history. This new clinic model is called the Pediatric Interdisciplinary Neurodevelopmental Clinic (PINC).

The Change or Improvement Made

A literature review and extensive consultation with policy makers, community agencies, GRH clinicians, and most importantly, parents and caregivers, highlighted three important priorities for clinic redesign: a greater focus on supporting functioning of children, ensuring equitable access, and prioritizing efficient use of clinic resources. The new clinic criteria are more flexible and consider diverse needs for support. The new clinic operational model also has shifted to allow for more flexibility and individualization of assessment to meet diverse needs of each child and family. Included in our implementation process has been the integration of an evaluation plan that looks specifically at the experiences of children and their families in PINC and which addresses the

priorities identified by families including support for service navigation and a focus on providing more culturally responsive care.

The Evidence of Success

There are several areas that demonstrate evidence of success:

- Parent/caregiver/child experience: Glenrose Patient Reported Experience Measure - We have recently begun collecting data from families who have gone through PINC. Preliminary results show that we exceed family expectations.
- Reach/communication: Invited and scheduled presentations and publications (See attachment A). There are other national sites now looking at creating similar programs.
- Relationship Building: Consultation in the past year with the PINC parent focus group, Maskwacis Talking Circle, Family Support for Children with Disabilities, Edmonton Fetal Alcohol Network, Caregivers Alberta, Métis Nation, Visiting Clinicians, Children Autism Services Alberta, Children's Healthcare Canada
- Access and Equity: Access Owl data available is available on a Tableau database. We also have started collecting data to support us in monitoring aspects of social context of families accessing our clinic.
- Efficiency: We now see more than twice the number of families with the same resources.
- Referring physicians are being asked to complete a survey about their experiences referring to PINC
- Team collaboration: A survey administered periodically internally reflects clinicians' experiences collaborating with each other and with families.

Results of these will be presented in Phase B, if this application is successful, moving forward.

Item of Support #1 [excerpt from a one-page letter written by a parent]

"Telling our story during my children's assessments was tough but the clinic made us feel comfortable. I'm happy they recruited me and asked me how they can make it better..."

Item of Support #2 [excerpt from an interview with parent]

[The applicant interviewed a parent and included a full summary of the interview with direct quotes as part of their submission.]

“Being in PINC allowed us to dig a bit deeper into issues related to school difficulties, socializing problems...I’m grateful because he’s struggled all his life and it’s not for lack of trying...now we have more knowledge.”

2. Family Mentor Program – Alberta Children’s Hospital (2026)

[Names were redacted to protect people’s privacy.]

The Opportunity for Change or Improvement

When a child is hospitalized, families experience emotional distress, isolation, and uncertainty. They are frequently unaware of the available resources to support them on their healthcare journey. A volunteer Bedside Connections program was developed at the Alberta Children’s Hospital (ACH) in 2013 to address this critical gap by offering empathetic, peer-based support rooted in lived experience. Trained volunteer peer mentors visited inpatient families to introduce available resources, share strategies for partnering with the healthcare team, and provide a listening ear.

These visits consistently received positive feedback from families and were encouraged and supported by leadership and staff. However, it was difficult to sustain and grow it as a volunteer program. We were asking volunteer parents with complex lives to commit to bi-weekly shifts and make what were essentially cold calls. It wasn’t a role that fit many volunteers nor could people commit for an extended period of time.

In 2024, we were fortunate to receive funding for a part-time position through the Alberta Children’s Hospital Foundation. This has allowed us to transition Bedside Connections into a paid role to support inpatient families. Building on what we learned from our experience doing Bedside Connections, we collaborated with our volunteer mentors, families, and staff to develop this new role. This included engaging the ACH Family Advisory Council to inform the resource content and a name for the program. Through this process, the Family Mentor Program was born.

The Change or Improvement Made

Three Family Mentors were hired who had firsthand experience with having a child hospitalized at ACH. They each received peer mentor and Connect Care training. Together they work four, four-hour shifts per week. They receive regular support through supervision and team meetings for ongoing knowledge and skill development.

The Family Mentors visit families in the hospital units, offering organic conversations, resource navigation, and referral facilitation. They document their visits within Connect Care and submit shift summaries, enabling responsive support and meaningful data collection. We worked with AHS Data and Analytics to develop a logic model and an evaluation framework which includes an end of shift summary report and a family experience survey. The use of Tableau Analytics has helped to build awareness across the site, identify actionable insights, and demonstrate the program’s impact on patient experience.

The Evidence of Success

The Family Mentor Program has significantly improved consistency, reach, and integration of peer support within clinical care. Family Mentors now provide support to ACH families in all inpatient units. In one year, 1,172 family visits occurred, an increase of 554% from the number of volunteer mentor visits in the previous year.

Families who completed the patient and family experience survey reported feeling more hopeful, informed, and emotionally supported after a Family Mentor visit. 100% of respondents recommend Family Mentor visits for others, citing the value of connecting with someone who truly understands their experience.

The program's success underscores the value of Family Mentor support in clinical settings and invites replication across healthcare systems.

Item of Support #1 [survey response]

- I really appreciated our Family Mentor - she was so kind and knowledgeable. It was so wonderful to speak with someone who can understand what it is like to have a child with medical needs and she encouraged me so much. This is a much-needed support in hospital because we as parents are often exhausted and overwhelmed, if not in shock, when our children are diagnosed and receiving treatment, and it is such a welcome change to speak with another parent, rather than just the medical staff. Having a Family Mentor makes the hospital feel less cold and impersonal. She was super helpful and provided us with many different resources that we would have otherwise had no idea about! We are very grateful to have had the visit today.

Item of Support #2 [survey response]

- The Family mentor came to my son's room on Day 3 of our admission. It was the first time I felt heard, seen and didn't feel isolated. She didn't rush like we were an item on a checklist. She took time to really hear me and provide support and resources suited to me.
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3. Calgary Zone Adult Music Therapy: (M)Powering Patient Care (2025)

[Video content, names, and other identifying details were redacted to protect people's privacy.]

Opportunity for change or improvement

In 2016, Foothills Medical Centre (FMC) Tertiary Neurorehabilitation received a small donation from a family, recently discharged. This family saw a need for more social and meaningful activities for rehabilitation patients during long stays recovering from neurological injury and disease. That donation, in addition to grant funding awarded by the Canadian Music Therapy Trust Fund, catalyzed what has become the Calgary Zone Adult Music Therapy (MT) Program: four acute care sites, 21+ units, >55 hours/week, 4000 patient visits in the last year (2023-2024), and four research publications.

Critical Care is but one area where MT services were integrated and studied by University of Calgary researchers. ICUs are high stress environments where patients experience physical and emotional discomfort due to their medical condition and life-saving treatments. Patient distress is commonly managed with sedation, especially during prolonged ICU stays. Other options like music have been explored to promote relaxation, reduce stress, anxiety, pain, assist in removing breathing supports during recovery or for end-of-life care. [Physician Name], ICU rehabilitation physician, advocated for music therapy due to clinical experience and long-term follow up data.

The change or improvement made

Once weekly for 2-3 hours, music therapists were introduced to FMC ICU, followed by South Health Campus (SHC), Peter Lougheed Centre, and FMC Cardiovascular ICU sites from 2018-2024 with support from National Music Centre (NMC) and Calgary Health Foundation.

To evaluate the impact in critical care, we consulted and received endorsement from 15 patient family advisors from the SHC Patient Family Advisory Council (The Citizen Advisory Team) and recruited four patient advisors, two student researchers, three ICU Music Therapists, and an AHS senior data & analytics lead to create patient, family and staff survey tools. We administered surveys between May-November 2024. Key results are summarized below in chart form, and narrative.

Evidence of success

ICU Music therapy is realistic, practical, and benefits patients, family members, and staff. All groups reported improvements in mental well-being and overall ICU experience. The patient and family survey tools were useful and easily administered. The most common reason for declining MT was "fatigue" at the time offered. Expanding services further would increase access and broaden the use of MT to assist in weaning off breath support, painful procedures or end-of-life care. We have also

demonstrated success in other units with published research sharing themes and quotes from neurological patients, families and staff for emotional support, pain relief, social connection, perceived enhanced recovery, and satisfaction.

Key Points of Chart Results:

100% of patients felt MT provides emotional support, 97% were satisfied, 100% wanted more MT, and 85% reported + impact on loneliness. Family felt 100% satisfied with MT for their relative, 96% felt + impact on their relative's stress, and 92% felt a + impact on their own stress.

Item of Support #1 [letter from family member, with redactions]

To Whom it May Concern,

Letter of Support for Music Therapy in Health Care Settings

Re: Calgary Zone Adult Music Therapy: (M) Powering Patient Care

During the fall of 2024, as a Patient Family Advisor with Alberta Health Services, I conducted patient and family interviews to understand the experience of music therapy at South Health' Campus, in the ICU. The studied music therapy sessions involved a professional music therapist connecting with diverse patients and families, at their ICU bedside. Each music therapy session averaged 30 minutes in duration and consisted of a music therapist playing the guitar and singing. The music therapist compassionately connected with the patients and families prior to the session and ensured that the music matched the interest of the patient and/or family member. The style of care provided by the music therapist aligned with patient and family centered care principles and contributed to achieving a respectfully engaged experience, where the quality of this shared relationship was of utmost importance.

This formal research amplified my anecdotal understanding that music has the power to holistically improve patient wellness and the quality of care experienced. As anticipated, the research findings confirmed my belief that music therapy is associated with overwhelmingly positive findings with patients, families, and health care providers. Patients and family members consistently shared they were *"very satisfied"* with the music therapy experience. Key findings from the research indicated that pain and mood improved, and stress levels decreased, demonstrating that music therapy can successfully improve both physical and mental health. When asked what could be improved or changed to make the music therapy experience better, patients agreed there was nothing to change and commonly replied *"we just need more of it."* From the health care provider perspective, front-line providers shared that music offered an opportunity to escape the stress and constant beeping sounds that are present in the ICU, suggesting that this form of therapy also has the power to protect their mental wellbeing.

From my own perspective as a patient and caregiver, I have observed how music can substantially improve the health care experience, parallel to these research findings, as described below.

- In the palliative care setting, as a caregiver to a friend battling lung cancer, I had the opportunity to incorporate music into her care experience, via playing music from my cell phone. Music in her final days provided an opportunity for her friends and family to connect and achieve a degree of peace that may not have been achieved without the application of music. Additionally, music offered my friend, moments of distraction from her severe pain and temporarily elevated her mood, when she was enduring a significant level of distress.
- In the long-term care setting, while caring for my [family member] in her final stage of life, I utilized music again, via playing music from my cell phone. I am grateful that I was able to connect with my [family member] in such a unique and special way, while playing music from her generation and faith inspired songs, that she would often hear in her church growing up. From my assessment, she experienced improved comfort, which was observable even when she lost her ability to verbally communicate, as evidenced by smiles and holding my hand tightly. For myself, as the caregiver, I felt a sense of healing and relief that I was able to contribute to creating a calming environment in an emotionally difficult circumstance.
- [redacted]...I have observed how music has been utilized with ease, in the pediatric population to connect and decrease anxiety with children at the Alberta Children's Hospital. My [family member] still recalls today [redacted] a health care provider played [music] at her request, when she was in the OR prior to an investigative procedure. She shared that this musical experience had the power to decrease her anxiety, making her feel safe, and improve her mood... [redacted].

In summary, I feel that a music therapist would have been invaluable in improving the health care experience in all my patient perspective examples above. I strongly support that music therapy is a safe and cost-effective form of medicine, that is appreciated across the lifespan, cultures, and various health care domains, defining it as a sustainable form of care to implement. Based on my meaningful experience(s), I am inspired to advocate for increasing-the frequency of music therapy in health care settings. Thank you for taking the time to review my personal and researcher lens that highlights how music in health care matters and the significant difference it makes in the lives of patients, families, and health care providers. Thus, I recommend, that music therapy ought to be deemed an essential support service, in all care settings in Alberta Health Services.

Yours Truly,
[Signature]

Item of Support #2 [patient video testimonial] [Redacted.]

4. Incremental Dialysis (2024)

[Video content, names, and other identifying details were redacted to protect people's privacy.]

The Opportunity for Change or Improvement

Incremental dialysis is an innovative, patient-centred program that matches dialysis frequency to patient need. Alberta Kidney Care and the Medicine Strategic Clinical Network have partnered with patients and healthcare providers to implement incremental dialysis across most of Alberta. Instead of the typical 3x/week dialysis, eligible patients have a gentler 2x/week start to dialysis at a healthcare facility. They are assessed regularly and increase dialysis frequency or switch to another treatment as needed. Patients have been involved throughout the development, implementation and evaluation of incremental dialysis in Alberta.

Previous Alberta research revealed that tailoring dialysis treatment to individual needs is a priority for patients. Incremental dialysis was identified as an acceptable solution. An initial patient focus group co-facilitated by a patient researcher confirmed support of the program, as well as shaped program design and patient education material.

The Change or Improvement Made

Incremental dialysis is innovative because it matches dialysis frequency to patient need compared to the standard approach of thrice weekly dialysis. It is a leading practice in person-centred care based on current research showing benefits to patients. This work addresses a gap in the literature regarding direct patient reported experience on incremental dialysis. It strives to support patients to self-manage their own care; patient education outlines expectations, possible symptoms, and active participation in care. We have shown that incremental dialysis is safe, well tolerated, patient-centered and additionally has positive impact on the healthcare system by increasing treatment capacity and reducing treatment costs.

Patients were active participants in designing the incremental dialysis processes, quality improvement framework and program evaluation. Patients had significant input into program priorities, strategies, education materials and evaluation tools through committees and working groups. They also contributed through surveys, interviews and focus groups. One of our patient advisors is highlighted in a patient education video, which was desired by patients and filled identified education gaps. Issues and suggestions raised by patients were used to improve the incremental dialysis program, and to advocate outside of the program.

Incremental dialysis acted on patient feedback in several ways. The program advocated for peer support based on patient advisory group requests. When patients asked for better understanding of when they may need more dialysis, we developed a tool to be piloted to address that need. Evaluation approaches and questions changed based on patient advisor input. Through interviews,

patients identified education and shared decision making as areas for improvement; in response, we developed a patient education video to better support patients.

The Evidence of Success

Incremental dialysis has improved patient experience. Incremental dialysis patients rated their quality of life higher than those on standard dialysis. In interviews, patients responded positively to the program; they especially appreciated the additional time not on dialysis. In focus groups, patients shared that they were treated with dignity and respect, they were satisfied with the program, and it improved their quality of life.

In conclusion, patients identified the need for incremental dialysis, shaped the innovative solution, and have benefitted from the program. Thank you for considering this application for a patient experience award.

Item of support #1 [patient's letter]

My journey with incremental dialysis began [date], 2022. Until that that day I really knew nothing about dialysis as a whole. Incremental dialysis was the best choice for me as it allowed me to keep working and the ability to maintain my home life while being able to get treatment. Two times a week makes sense especially for people like myself who still voids allowing the kidney to do as much as they can for as long as they can.

Throughout the last year and a half I've met some truly remarkable caregivers from the doctors to the nurses and also the staff that maintains the machines and the staff who maintain a safe and clean environment. They have not only cared for my medical needs but also cared for me as a person. At the beginning stages of my journey there seemed to be an overwhelming amount of information but I've come to realize that it was to arm me with as much opinions possible. I at no time felt alone in my journey there has always been someone to answer any questions I had or to reassure me that my feelings of fear and anxiety were valid. I believe that the staff as a whole are doing everything they can to create an environment of care and understanding but throughout this experience I observed many of the challenges they face being short staffed and not having enough time to spend with patients like myself. Even though I believe our system is flawed I'm thankful for the people who show up everyday and truly make a difference.

Item of support #2 [patient's digital story, with redactions]

Across the Kidney Care Continuum: One Patient's Story

I was diagnosed with polycystic kidney disease at [redacted] years old. At [age redacted] and with the symptoms of kidney failure peaking, I had to go on dialysis. I started to worry about how would

I run my business being at the hospital three times a week? How would it impact vacations and time with my family? What would my quality of life be like? It wasn't just me who would be affected, it was all the people around me.

....I didn't know what Incremental dialysis was, but I liked the sound of it...[redacted]...anything to minimize the disruption to my business and family.

In our first meeting I learned that incremental dialysis was not for everyone. People with residual kidney function could require less dialysis. I learned there was additional monthly testing that was prerequisite, and it could lead to further restrictions on diet and fluid intake.

But 2 days per week would give me so much more quality of life, even if I would eventually have to transition to 3 days per week. After a few meetings I understood enough to know that I was eligible for the program, and I was ready to be an active participant in that discussion when it arrived. Dialysis was hard on me. By the end of treatment, I had a lot of pressure in my head that often developed into a migraine. I always felt tired and washed out, like a bad hangover... and the rest of the day was a write off. I felt so lucky that I only went two days a week.

In time I was able to transition to Home Hemodialysis and I was lucky enough to receive transplant in [redacted] 2022. Throughout the year I spent on hemodialysis, my residual kidney function allowed me less dialysis the entire time. Looking back I am not sure how I would have managed 3 days per week of in centre dialysis to start, it would have been so difficult.

I am grateful for the incremental dialysis program, as it recognizes that all those starting on dialysis are NOT the same, reducing the already heavy burden of kidney failure.

Please follow the link below to view digital story. [Redacted.]
