Story Medicine: Piloting Narrative Exposure Therapy to Support Healing for First Nations, Inuit, and Métis Women Who Have Lost Loved Ones

Final Project Report





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A Message From Well Living House Director Dr. Janet Smylie

It takes a village to design, implement, and evaluate an Indigenous trauma therapy. On behalf of Well Living House (WLH), I want to acknowledge the current and past members of the Story Medicine Advisory Council, for their guidance and feedback during the design and implementation of story medicine therapy and the linked research protocol as well as the development and sharing of dissemination materials, including presentations and this report. Our team would like to honor Elder and Knowledge Keeper Carol Terry who offered her guidance, knowledge, wisdom, prayers, and traditions in developing this research project from the very beginning. Indigenous midwives Cheryllee Bourgeois, Kimberly Orton, and Sara Wolfe each made formative contributions to the design and implementation of this project, even while they were very busy advancing birthing and reproductive health care, and for this our team is are extremely grateful. This project was gifted with the amazing project co-ordination skills of Jessica Syrette and then Genevieve Blais. Their caring and skills were key to ensuring the project was implemented in a good way. I couldn't have imagined a better group of trauma therapists and research co-investigator colleagues to work with than Tessa Culthoff and Nicole Muir. Your healing skills, insights, commitment, and experience were foundational to this project. Funding support from the Patrick and Barbara Keenan Foundation in 2016 made this project possible. We hold up the generosity of the Keenan Family as a timely and exemplar act of Reconciliation.

We honour the memory of all missing and murdered Métis, First Nations and Inuit women, girls, and 2SLGBTQQIA people including the spirits of the missing or murdered whose families shared with us. We want to thank and acknowledge the family members who shared their painful stories, truths, experiences, and knowledge with us. We honour your strength, courage, and perseverance in seeking healing for the loss of your grandmothers, mothers, sisters, daughters, aunties, nieces, cousins, and close friends.

All Of My Relations, Janet



¹ 2SLGBTQQIA+ - 2-Spirit (Two-Spirit), lesbian, gay, bisexual, trans, queer, questioning, intersex, asexual. The + where used denotes the diversity of remaining identities not covered in the acronym. Lezard et al. (2020) MMIWG2SLGBTQQIA+ National Action Plan Final Report.

Background

Growing public recognition regarding the disproportionate levels of violence against Indigenous women, girls, and 2SLGBTQQIA+ can be directly linked to decades of advocacy from survivors and their family members and Indigenous and allied organizations [1]. Repeated calls for a national inquiry to investigate the alarming numbers of missing and murdered indigenous women and girls resulted in the launching of The National Inquiry Into Missing and Murdered Indigenous Women and Girls (MMIWG) on September 1, 2016. Testimonies from survivors and family members who had lost loved ones and family members was identified as a key element of the this Inquiry. After hearing from hundreds of families, survivors, family members, Indigenous leaders, knowledge keepers, communities, experts, and institutions a final report, including Calls for Justice was released on November 1, 2018 [2].

Upon the announcement of the National Inquiry Into MMIWG, Indigenous leaders, health professionals, and family members who had lost loved ones voiced concerns regarding testimonial processes and likelihood that they would contribute to emotional distress and re-traumatization for those who participated in telling their stories and for those who listened to them [3]. Remembering and retelling the stories of violence and loss of loved ones can have a dysregulating effect and increase post-traumatic stress reactions and feelings of depression, especially if done in a context that is experienced as unsafe, for example a legal proceeding [4].

In response to these calls for increased mental health supports for family members who had lost loved ones during the National Inquiry into MMIWG, Well Living House at Unity Health launched the Story Medicine Pilot Project in 2016. With support from the Patrick and Barbara Keenan Foundation, we developed and evaluated a new, Indigenous specific "Story Medicine" trauma therapy that build upon and maintained key elements an existing and demonstrated trauma therapy known as Narrative Exposure Therapy (NET) [5]. This report details the development and piloting of Story Medicine.

One of the original intentions of the Story Medicine project team was to see if the new Story Medicine trauma therapy could be used to support survivors and family members to produce their testimonials in advance of MMIWG proceedings in a culturally safe, therapeutic environment. Although timing and MMIWG processes did not allow for this, multiple participants and team members in the Story Medicine project were involved in various aspects of the National Inquiry Into MMIWG and reported that the Story Medicine was beneficial for them.

Predictably, throughout the inquiry, community leaders and family members identified ongoing gaps in emotional, psychological and spiritual support for those testifying [6]. Subsequently, the need for mental health supports were further highlighted in the Calls for Action included in the National Inquiry's final report. These Calls for Action highlighted the importance of trauma informed training for those who work with Indigenous peoples. They also highlighted the importance of continuous and accessible community-led healing programs and support for family members of the Missing and Murdered Indigenous Women and Girls and 2SLGBTQQIA+ people.



Story Medicine Pilot Project Study Description

Long Term Goal

The long-term goal of the Story Medicine Project team was to ensure that Indigenous peoples had access to culturally safe care to enable healing from traumatic experiences. This included First Nations, Inuit, and Metis peoples who had lost loved ones and experienced other traumas.

Story Medicine Pilot Project Aim

The specific aim of the Story Medicine Pilot Project was to design and test the usefulness and community relevance of an Indigenous narrative trauma therapy. We aimed to see if the new therapy improved the mental health and wellbeing of Indigenous people who had lost loved ones.

Project Overview

The project was designed and implemented in partnership with affected families and was guided by an Indigenous Advisory Council. The Story Medicine therapy built on the basic structure of the original NET, while adapting and adding Indigenous cultural, spiritual and healing practices. To see if Story Medicine therapy was making a difference, we originally designed the study to compare depression, anxiety, and trauma symptoms for those who had completed the therapy to those who had not yet started the therapy. When the COVID-19 pandemic interfered with recruitment and completion of therapy, we changed our design and instead compared measures of depression, anxiety and trauma symptoms before and after treatment for the six participants who completed the Story Medicine therapy. Results, interpretation, recommendations, and reporting were completed with the support of the Indigenous Advisory Council.



Methods

Project Partnerships And Governance

We started by forming a project Advisory Council that included a family member of a MMIWG, an Elder/Knowledge keeper, a health/service provider, and a person working in the provincial Ministry of the Attorney General's office. The purpose of the council was to make sure that the study was of strong benefit to Indigenous communities. Additionally, the Advisory Council provided guidance on ethical issues, instructed on how to do and plan the study, helped flag and fix any things that may end up harming people, helped find study participants and helped to share outcomes of the study.

See **Appendix A** for the full Story Medicine Advisory Council Terms of Reference. See **Appendix B** for the full Project Team. See **Appendix C** for the Advisory Council Members.

Study Design

As mentioned above, to see if Story Medicine therapy was making a difference, the study team originally designed the study to compare depression, anxiety, and trauma symptoms for those who had completed the therapy to those who had not yet started the therapy. To achieve this, we randomly placed clients in either an immediate treatment group or control (waitlist) group of clients who would access the therapy after a waiting period. We did this because it is a strong method for understanding if a therapy makes a difference and also, due to the limited number of therapists, some clients were going to have to wait for therapy regardless. When the COVID-19 pandemic interfered with recruitment and completion of therapy, we changed our design and instead compared measures of depression, anxiety and trauma symptoms before and after treatment for the six participants who completed the Story Medicine therapy.

Participant Recruitment

Story Medicine was made and used to support the testimony and healing for Indigenous families who have lost a family member (i.e., a family member has gone missing or been murdered). We respect and honour the families who were not ready or who chose not to participate in inquiries, therefore family members did not have to be involved in the Missing and Murdered Indigenous Women and Girls (MMIWG) inquiry to do Story Medicine.

We began recruitment for the Story Medicine project in May 2019. We ended recruitment for the Story Medicine project in December 2021. We additionally put a hold on recruitment of new clients during the COVID-19 pandemic (March 2020 – November 2021).



Clients were recruited by hearing about Story Medicine from friends or family and were able to be in the study if they:

- Self-identified as Indigenous (First Nations, Métis, or Inuit)
- Had a MMIWG family member/kin tie
- Were over the age of 16
- Were suffering from the effects of PTSD in a way that impacts their daily life
- Were willing and able to be part of Story Medicine either in person or via video

Anyone who was pregnant was unable to be part of the study, because working through traumatic experiences could make them feel worse in the short term and this might be unhealthy for the growing baby.

The Intervention (See also Table 1)

In Story Medicine therapy, traumatic events are looked at again in detail. All the important positive and negative life events are shown in the client's entire life from their birth to the present day.

In the first two sessions, therapists explained how Story Medicine works and how symptoms (like anxiety) can be reduced by doing this therapy.

In the next session, clients work with the therapist to lay out a string, ribbon, or other material that is a symbol for their lifeline. The lifeline starts at the client's birth and continues until the present day. Clients can pick flowers or objects that are meaningful to them to mark the positive moments in their life that they strongly felt and remembered. The client is then asked to pick stones or another item that has a meaning for them to mark the strongly remembered traumatic events.

As clients place the stones and flowers along their lifeline, the client names each one, tells when it happened and where it happened. For example, a client may remember the moment that their partner asked them to get married. They might call this event "engagement" and say that it happened in 2010 in Toronto.

With the help of therapists, at each subsequent session clients "story tell" an important traumatic event in their life. The therapist asks the client many questions to help them remember as much detail as they can about the traumatic event. The therapist also asks the client to talk about their thoughts and how their bodies felt (e.g., their arms felt frozen). The therapist then asks the client how they feel and think about this past traumatic event right now. This is to help the client keep the trauma in the past. Telling the story of this trauma will slowly heal the pain that is connected to these traumatic memories.

Therapists then write down everything the client said in each session, including all the details the client remembered and how they felt (and feel) about the trauma. Clients get this story that has all their traumas written down at the end of treatment. The client decides with their therapist what to do with this long story. Figure 1 shows the method of the Indigenous Narrative Exposure Therapy.

Please visit the following links to access the assessment tools used in the Story Medicine project:

- Story Medicine History Taking Interview
- Story Medicine Screener: ACE+: Adverse Childhood Experience Plus Questionnaire
- Story Medicine Sociodemographic Survey
- Story Medicine Mental Health Questionnaires:
 - PSS-I 5 (PTSD)
 - PHQ-9 (Depression)
 - HAM-A (Anxiety)



Story Medicine is a version of NET that has been changed for Indigenous peoples in Canada. It is rooted in Indigenous ways of being; actively addresses colonialism and linked multi-generational trauma; and centres Indigenous traditions of using storytelling to heal.

Key adaptations in Story Medicine include:

- Starting with strength-based conversations about the client's purpose and worth;
- Allowing the client to decide for themselves what their preferred expression of Indigenous identity and spirituality is;
- Inclusion of assessment of multigenerational trauma at baseline and ensuring that experiences of multigenerational trauma are understood and addressed in therapy sessions;;
- Adjustment of lifeline material to ribbon scarves, sweet grass (vs rope which is used in NET as rope can be negatively connected to suicide in some Indigenous contexts);
- Pivoting from representing traumatic events on the lifeline with stones to alternate materials such as shells and burnt wood when relevant as Indigenous stones are considered sacred by many Indigenous peoples. Joyous events were represented with materials like shells, tobacco ties, feathers, flowers, rosehip;
- Completion of safety plans with clients at baseline including lists and/or referrals of relevant local supports and resources;
- Use of Ontario Telehealth and Zoom for clients in communities outside of Toronto to enhance treatment access; ;
- Inclusion of both western religion and/or Indigenous spiritual beliefs as per the client's choice;;
- Self-location of therapists regarding their Indigenous identity, ethnic and/or racial backgrounds;
- Indigenous customization of the client manual e.g., addition of Indigenous creation story;
- Availability of smudging before, during, & after sessions if desired by client.

As pointed out above, therapists were prepared to talk about ways that colonialism and multi-generational traumas could come up during sessions including:

- Abuse in residential school;
- Child and Family Services or child welfare involvement such as foster care, 60s Scoop;
- Lateral violence;
- Racism & Discrimination;
- Mistrust of healthcare (for example, accessing Ontario Telehealth at hospitals).

Session	Purpose
Screening (With study coordinator)	 Explain Story Medicine study using a short description for interested clients Review the information letter and the consent form
1: Introductory Session (with study therapist)	 Introduce each other Build a trusting relationship and safe environment Set up a foundation of strength for the client (e.g., smudging) Go over the consent form Go over that all the information in sessions is private and confidential Go over what will be covered in treatment Do the History taking form Sociodemographic Information gathered (e.g., age) Do the mental health assessments on PTSD, Depression, and Anxiety Do a Safety Plan (e.g., talk about which supports the client has)
2: Psychoeducation (with study therapist)	 Talk about what strengths the client already Discuss what their Indigenous identity and spirituality looks like Talk about trauma and explain how Story Medicine treatment works Go over the fear network, PTSD worksheet, and client guidebook resources Get ready for the storytelling and pick the Lifeline objects
3: Lifeline (with study therapist)	 Ask client to pick lifeline materials (e.g., flowers) from bundle Discuss important life events and then use a stone or a flower to mark this event Record lifeline in a way that feels safe to the client (photograph or drawing)
4: Session 4 (with study therapist)	 Story telling of a traumatic event Choose a traumatic event Tell the story of the traumatic event and highlight feelings, details, and body sensations in the past and in the present. Therapist writes down the client's story of the traumatic event discussed in the session
5-8: Sessions 5 and the following sessions	 Written story from previous session is read to the client Client corrects or adds details the report Recognize and story tell another traumatic event Tell the story of the traumatic event and highlight feelings, details, and body sensations in the past and in the present. Therapist writes down the client's story of the traumatic event discussed in the session
9 & 10: Closing Sessions (with study therapist)	Closing Session 1 • All the stories of the traumatic events are read to client and all final corrections are made • Report/testimony is signed by the client • If closure has been reached, the treatment is closed • Report handed to or mailed to the client with picture of Lifeline/Lifecycle • Healing Bundle is given to or mailed to the client Closing Session 2 • After-treatment Interview with the client • After-treatment Mental Health assessments
10: 3 Month Follow-Up Visit (with study therapist or study coordinator)	 Final Interview Final Mental Health assessments Evaluation/Personal Reflection Discuss Healing Bundle again Make sure the client has supports e.g., a therapist in their home community

Table 1 - Therapy Session Outline

Information Gathering

When clients told us that they wanted to be included in the study, they first signed a consent form. After that, we gathered some information to help us see whether Story Medicine helped heal clients. We also gathered some information to make sure that the clients were safe during their therapy.

The information we gathered included questionnaires that asked about:

- Multigenerational trauma
- The client's current life situation, mental health concerns, and things that were causing them stress
- Post-Traumatic Stress Disorder (PTSD)
- Depression
- Anxiety
- Safety concerns and a safety plan (e.g., client was worried that they would get really upset after a session, so together with the therapist, they made a plan to help with this)

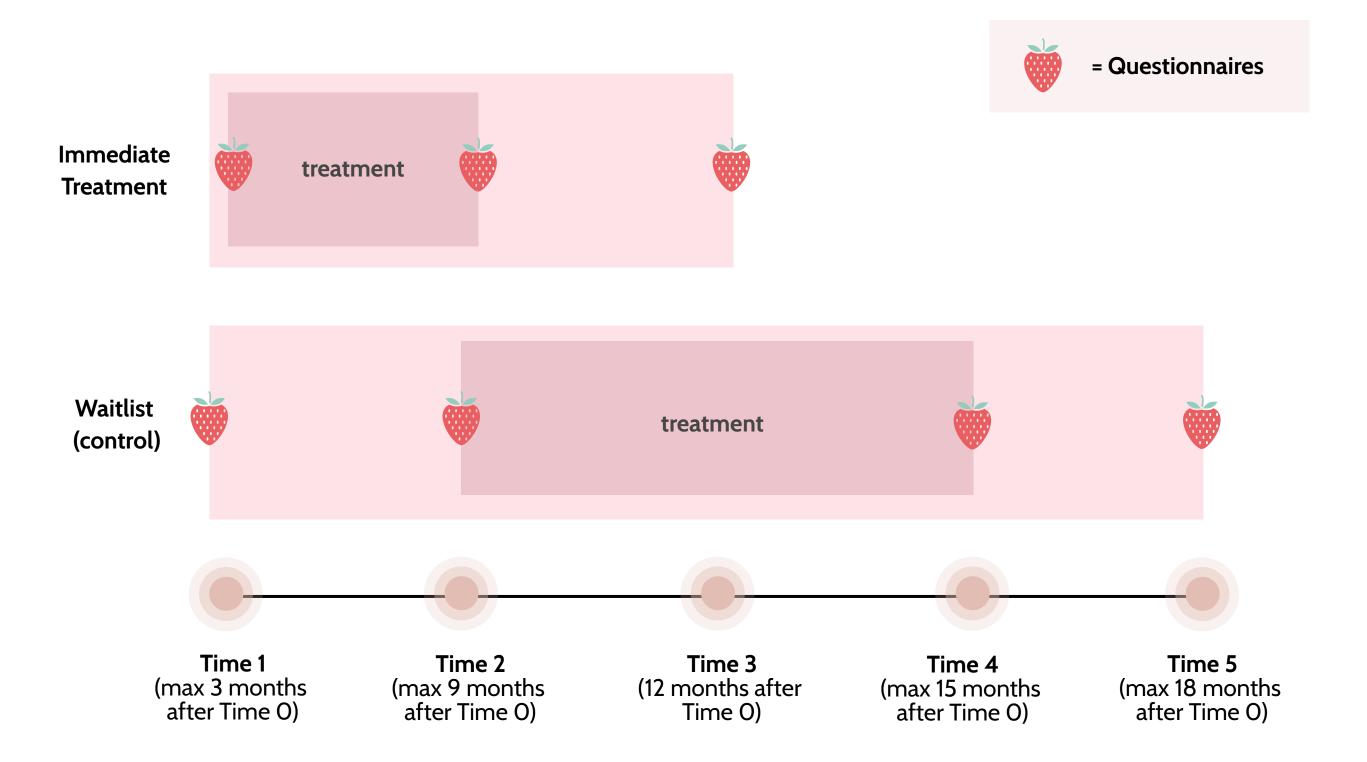
We then did a random draw to see which clients would begin treatment immediately and which would start treatment later. We wanted to make sure all clients would be able to access the therapy but only had enough therapists to provide therapy to a few people at a time. Deciding who started right away and who needed to wait using chance made sure everyone who joined the study had equal access to immediate versus delayed treatment and also helped contribute to a study design that would better help us understand if the therapy worked or not, since it helps reduce differences between the immediate and delayed treatment groups.

The immediate treatment group began their therapy within 3 months of doing all the assessments. These clients met with their therapist on a weekly basis and completed up to 10 sessions over three to six months.

The wait list group (delayed treatment) redid all the questionnaires again when they started treatment with their therapist and then completed up to 10 sessions over three months.

Both groups did their questionnaires again immediately after completing their last Story Medicine treatment session. Then, three months after their therapy ended, we repeated the questionnaires, along with a short personal reflection and evaluation interview. This interview gave clients a chance to tell us how they thought Story Medicine had helped them heal. We did this interview and the questionnaires three months after treatment because Story Medicine sometimes continues to help clients heal even after treatment is done.

Below is a picture representation of the Story Medicine timeline for both groups. Time zero is when the clients completed consent. Strawberries represent when the questionnaires were taken.



How We Evaluated The Intervention

To see if Story Medicine helped clients heal, we looked at:

- 1. Whether PTSD, Depression, and Anxiety scores improved by comparing scores from treatment began to 3-months after treatment was completed.
- 2. Personal Reflection interviews and evaluations from all clients: Clients talked about whether their lives seemed better before and after the therapy, and also, what it was like to actually do Story Medicine. These client reflections could include things like how they felt about the treatment manual before, during, and after Story Medicine.

How We Pivoted Recruitment and Treatment During The COVID-19 Pandemic

When the COVID-19 Pandemic and associated lockdowns began, we were in the middle of recruitment of participants to the Story Medicine recruitment and also engaged in therapy with several already enrolled Story Medicine participants. We could no longer meet with therapy participants in person at this time as it may have resulted in exposure to COVID-19. As a result we stopped recruiting new clients (from March 2020 – November 2021) and made arrangements for clients engaged in therapy who were meeting with their therapists in person to be able to pivot to online therapy using Ontario Telemedicine Network (OTN) or zoom. Some therapy participants chose not to make the switch to online therapy as they did not feel comfortable with the change from in person to online therapy sessions. These participants waited until they could continue their therapy in person or dropped out of the project.

How We Analyzed The Information We Gathered

The final Story Medicine participant completed treatment and their three month follow-up interviews in March 2021.

We then used statistics to see if there were any meaningful changes in Depression, Anxiety and Post-Traumatic Stress Disorder scores for the six clients that completed Story Medicine therapy. We also looked for meaningful patterns in the information that was gathered upon enrollment by all 12 clients that enrolled in the study, including both those that completed and didn't complete Story Medicine therapy. Responses to the open-ended questions from the personal reflections interviews (done 3 months after therapy was completed) were closely reviewed by two project therapists, who searched for emerging themes and patterns. During this review, the therapists kept in mind how colonialism could harm clients and they also looked for clients' strengths



Results

A total of 12 family members enrolled in the study; 6 of these family members completed treatment and 3 participants withdrew due to COVID-19 related stressors; 3 were lost to follow-up.

Of the 6 family members who completed Story Medicine, 5 Family Members Completed Immediate Treatment and 1 Family Member Completed Delayed Treatment.

Descriptive Baseline Information

For all twelve clients enrolled in the study:

Average Age of 54.5 Years	Identified mostly as female (83.3%) and included one transgender person (8.3%) and one "other/you do not have a category that applies to me" (8.3%) person
33.3 % of clients with children had Child Protection Agency involvement in the care of one of their own children	58.3 % of clients had Child Protection Agency involvement as children

At The Beginning Of Therapy

For the twelve clients enrolled in the study:

- Clients reported many symptoms:
 - Anger and shame (91.7 %)
 - Numbing/dissociation (75 %)
 - Difficulty sleeping (75 %)
- They also reported tension reducing behaviours:
 - Eating (33.3 %)
 - Alcohol (16.7 %)
 - Drug use (16.7 %)
- Clients had moderately severe baseline depression
- Clients had moderate to severe anxiety at baseline
- Clients also had high severity of PTSD symptoms at baseline

Changes In Depression, Anxiety And Post-Traumatic Stress Disorder Among Clients

We were able to look at pre and post treatment for changes in Depression, Anxiety and PTSD scores for six clients (5 Immediate, 1 Waitlist). As mentioned above, due to COVID-19 recruitment and treatment interruptions, we combined results for immediate (5) and waitlist (1) clients.

The information we gathered showed that Story Medicine did *lower depression (PHQ)* and anxiety (HAM-A) symptoms for some clients. When we looked at each client, we could see the differences for each of these scores over time, with most of the clients showing both immediate and longer lasting benefits. We also saw that a few individuals had an increase in symptoms. It would be easier to understand with certainty how much and for whom Story Medicine helps if more participants had enrolled and completed the study – unfortunately the COVID-19 pandemic interfered with enrollment and completion of therapy for some participants

How Did Story Medicine Affect Depression?

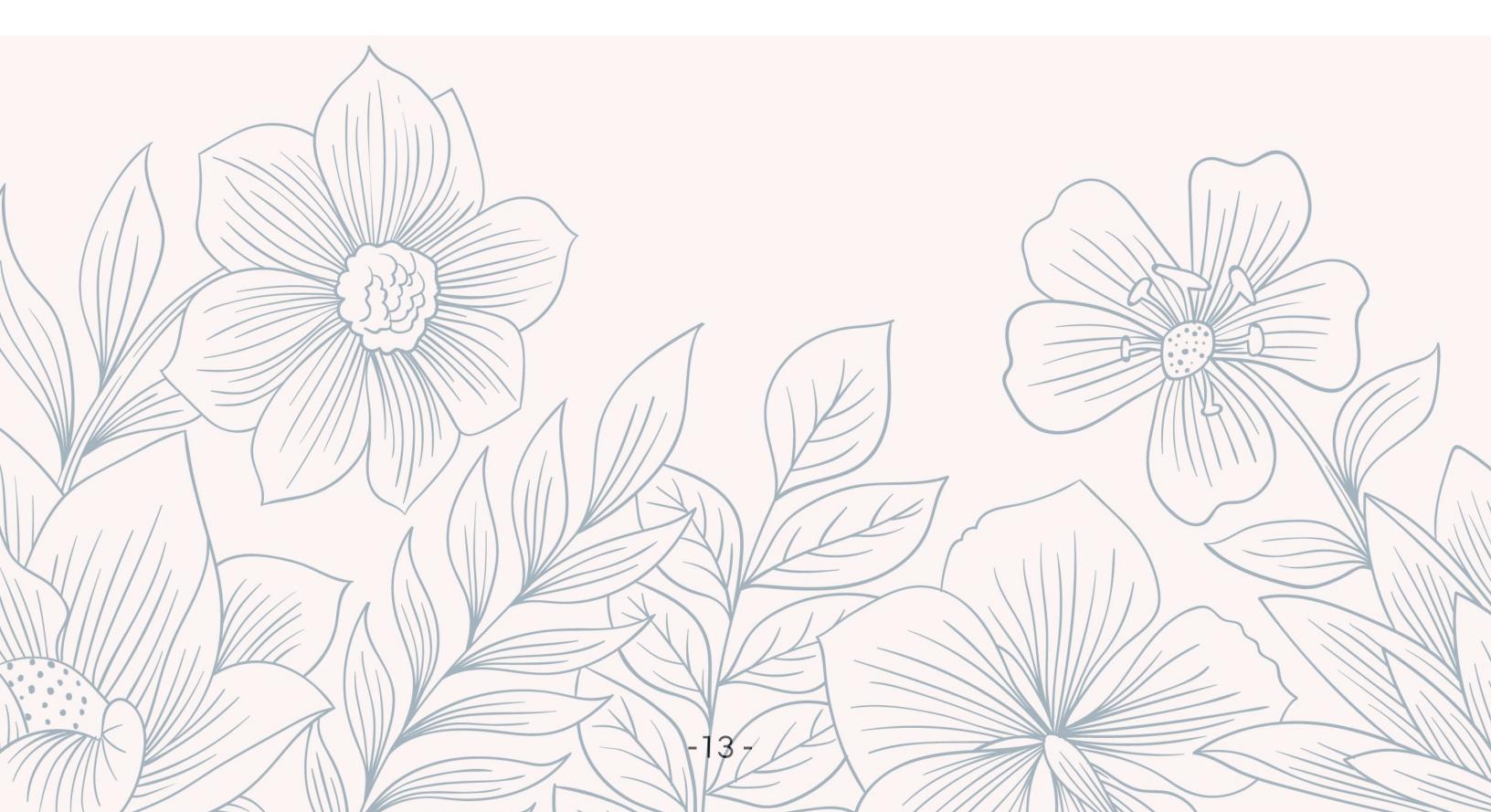
We saw an immediate and longer lasting improvement of depression for some clients and not for others. There was not clear evidence of a strong and consistent impact of Story Medicine across clients. This could mean that Story Medicine may be working for some clients better than for other clients.

How Did Story Medicine Affect Anxiety?

The results for anxiety scores were also mixed. The information we gathered did indicate that there was a lowering of anxiety symptoms after therapy for most of the clients, but not all clients. For many of the clients with reduced anxiety after treatment, these benefits lasted at least three months after therapy was finished.

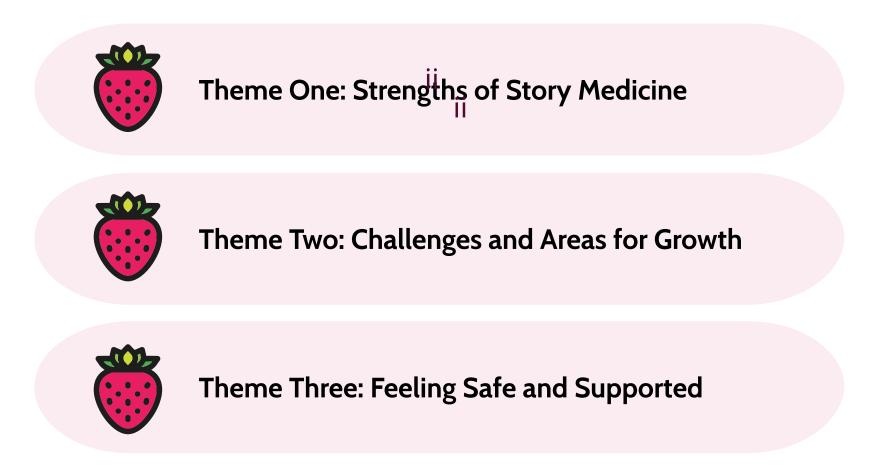
How Did Story Medicine Affect PTSD?

The impact of the intervention on PTSD scores had the most different responses; some clients experienced an increase in PTSD scores after Story Medicine, while others saw a reduction at the end of Story Medicine and then an increase three months after Story Medicine ended.



Personal Reflections and Evaluations

We looked at the personal reflection interview questions that included how clients felt about their quality-of-life outcomes and the experiences of Story Medicine after it had ended. We also looked at how clients felt about the Story Medicine client manual and their mental health needs before, during, and after Story Medicine. Overall, we saw three different themes.



Theme One: Strengths Of Story Medicine

Most clients, but not all, experienced an improvement in symptoms and felt better after doing Story Medicine. Most clients had a good experience overall, liked the therapy, and found it personally helpful.

All clients thought Story Medicine would be a useful tool for their community and almost all would recommend Story Medicine to others. One client, for example, said that:

"Yes I would definitely recommend this to friends and family. There's a lot of people out there in our community who need this kind of healing, who need this kind of help. I actually wish there were more sessions, because when you're dealing with what we have all dealt with, there are just so many things to cover, and so much to work through because of our histories and all that has come along with settler colonization and residential schools, and foster care, and the women in our families who have been taken from us or who we still don't know where they are and how we are dealing with all of that. I definitely think this could be used to help those families."

One client talked about the role that Story Medicine could play for those in their community who had experienced trauma or loss of a missing or murdered loved one

"For those with MMIWG I absolutely I think it's a fantastic adaption of narrative therapy – I'm familiar with EMDR and narrative exposure therapy and other narrative forms of therapy. I think it's a great adaptation to Indigenous communities especially around those with MMIWG"

There were several perceived strengths of the Story Medicine therapy. These included the Lifeline part of Story Medicine:

"I did particularly like the lifeline; I like that it included all significant events, not just the bad ones. I liked that I was able to receive it and figure out what to do with it. I haven't put it in the sacred fire but that's what I will do when the time is right. It's also really helpful and good to have all the events and what we talked about written up and provided and moving forward I may continue to reflect on it over the course of time, or perhaps I'll never look at it again."

"My counselor was really great, and I had a good experience. I really liked the lifeline part, and building that and using items on the lifetime that meant something special to me, so I could represent my life the way I wanted to"

"I think for sure the best part was being able to put together my lifeline and lay out everything in that really physical, tangible way, it made it easier to make sense of all the things that have happened in my life and look at it from the bigger picture. Building that and adding to that as we went along was really helpful."

Other clients found the education sessions helpful:

"I really liked the lifeline and the psychoeducation, learning about some of the reasons I was suffering and feeling the way I was. So like, the science behind that, that was really great to learn about"

Others spoke of how including their culture had a positive impact on their healing. One client, said:

"Our community can really use tools like this, these healing tools. We need everything we can, in ways that makes sense to us, that isn't imposed on us from those that don't understand our issues or don't understand our needs or our histories. That's what really made this therapy helpful from a lot of other therapies out there, especially the questions around residential schools and intergenerational trauma, and ceremony, and smudging, that really helped set the stage that you knew you were understood and you knew that these therapists were going to be able to take care of you and understand you in a way that I think a lot of other mainstream counseling doesn't."

"I really like how we were able to smudge and bring that into difficult parts of the therapy or at the beginning or at the end to help reground myself."

Others talked about how the Client Manual was helpful

"The manual was helpful because it had everything laid out, and it had some really helpful pictures and explanations about some of the background information on PTSD and memories, and even the NET method itself."

"I really liked that there was a lot of our own cultural knowledge that was part of the manual, and seeing myself in the therapy, feeling that connection and seeing the ways our knowledge was included in the manual. I liked having the manual handy too, so I could revisit some of the pyscho-educational stuff, or read it in my off time, or before sessions just to jog my memory."



Theme Two: Challenges And Areas For Growth

While most clients had a good experience overall and liked the therapy, clients also talked about areas for improvement or where they met challenges in their therapy.

The challenges/difficulties for some included:

Feeling safe in person at hospital institutions and Ontario Telemedicine Network (OTN) Interview spaces. For one client, this was a hospital where they had bad experiences in northern Ontario.

"Like I said, it was hard sometimes just scheduling the appointments and since I didn't live in the same city as the counselor, just going into the local Indigenous health agency or hospital and doing this over OTN wasn't always the easiest way to connect with my counselor, or some of the people at that agency weren't always the most friendly, or easiest with some of the staff there."

Another client experienced other barriers with therapy over Ontario Telemedicine Network (OTN):

"Well, I needed to be at a place that had OTN, so sometimes just going to the building wasn't always the easiest, as they were setting up the camera or were having technical issues or what not. It could be distracting with the camera and looking at the screen to talk to my therapist, and not having them in the room with you, when I was feeling overwhelmed."

Some clients talked about the need for dedicated space:

"I think that it would be easier if there was a more dedicated space for me to go to, or be in the same city as the counselor. My counselor was great, she was so helpful and really helped walk me through the sessions and keep track about what we had talked about. But it still would have been easier to be there in person to talk about some of these really difficult things, that maybe was a bit more isolated or separate from the main health building - you know where there are people at that building for a whole bunch of other reasons - or somewhere away from the craziness of home, work, family; these emotions come up that are so overwhelming so just having that space would have been even more helpful. Also like I said maybe just having the appointments spaced closer together so it didn't take as long as it did, so maybe some more dedicated time to finishing up all of the sessions"

"Like I said, it was hard to go through your memory and try to relive some of the things you really have worked hard to push down, just in order to get through your day-to-day. It could be a bit unsettling at times and like I said it was hard to go home or to work right after and keep it together. I don't know if this could somehow be offered in an intensive way where there isn't this huge space between the therapy sessions or you go somewhere for a couple weeks to do the therapy and the work, with other types of support around. Where there is a dedicated space for people to work through this and have all the supports around you."

"Sometimes it was hard getting the time off work or making sure someone was able to watch the kids. It was hard reliving a lot of the horrible memories about my family, and then going home and trying to be a mom or be with my family that same night. But I always felt a bit better the next couple days having talked about it."

"Well it was frustrating because when you don't have a lot of memory, you don't have the material to work with and I did end up finding I felt more triggered than really any healing—the bad memories, they weren't coming through for me in my daily life, so during treatment this was disruptive to my daily life, and I was being triggered in ways that I hadn't for a long time. I'm not sure if it was useful or just re-traumatized me more, as I hadn't thought about these things in long time, so I felt very messed up after the sessions."

A couple clients also noted the gaps in mental health care and need for support between appointments:

"I think this is a really great way for us to heal or begin to heal from everything that has happened to us. But it's not an end all be all to our trauma and what we face every day because of it. But I think It would be great to include along with other ways of healing, other types of therapy or even traditional counseling ways we already have, or other ceremonies that are available to us."

"I think, I just wanted a bit of relief from the everyday depression, some of the ways which these memories have affected me and my family. I wanted to try it and see if it could help with that, and it really did. But from what we have faced as a community, sometimes it feels like the healing goes on for a long time, that it doesn't just get fixed with one or two or three things. We need so many of these kinds of therapies offered to us, these kinds of therapies that are for us specifically as a community."

Having a hard time remembering traumas or memory loss also seemed to get in the way of trauma therapy for some. For example, one client expressed:

"I don't really think it worked for me; this is not because of a fault of anything in the treatment itself, it's just not suited for my particular circumstance because part of my condition is I don't have a lot of memories, so it's really hard to work with this method. A lot of my trauma happened in childhood, and I have lost a lot of memories from those times to help survive."

"Like I said, just going back into my memory, sometimes as you get older, there is just so much that gets built up over time, trying to remember farther back was a bit of a challenge at times."

Clients also talked about needing more sessions in their therapy. One client shared, for example:

"Absolutely, it would be easier if there were more supports, more sessions with [my therapist]. I still need help processing. I've done a lot of talking before but it felt like talking. This is the first time it felt like helping. I know my family is worse-off than I am. I always felt that relatives of mine would benefit more, and I didn't want to take the space because they thought the spot would go to someone else who needed it. Whereas when I did it, I realized that actually I did need it. During this process, I ended up with a stalker, I had to work through that before I could do more with [my therapist]. These things are still perpetrated against us. We're doing this healing, but things are still happening to us."

"There's a lot of people out there in our community who need this kind of healing, who need this kind of help. I actually wish there were more sessions, because when you're dealing with what we have all dealt with, there are just so many things to cover, and so much to work through because of our histories and all that has come along with settler colonization and residential schools, and foster care, and the women in our families who have been taken from us or who we still don't know where they are and how we are dealing with all of that. I definitely think this could be used to help those families."

Scheduling and a busy life also presented challenges for some clients. For example, one client shared:

"I think just sometimes making the time in a busy schedule for yourself. A lot of this was harder too during the school year, or during busy times at work, being able to find a space and quiet space to finish up the sessions or do the lifeline work."

"Sometimes it was hard getting the time off work or making sure someone was able to watch the kids."

Theme Three: Feeling Safe And Supported

Almost all clients shared that they felt they were able to develop trust as they felt safe and supported during their therapy.

For example, one client was able to receive support in transportation to their appointments:

"I can't think of anything right now that I would change in a way that would have helped me better, I was given lots of support around transportation to and from my appointments and that's really what I needed to make sure I got there. I think it would have been great to be able to attend them in person, that would have been a bit easier maybe...It was really great to get the support from the counselor and be able to get all the support getting to and from my appointments, that doesn't always happen with other counselling, all that extra support."

Finally, one client shared the following thoughts about their therapist, which we emphasize here as it includes key feedback regarding culturally safe engagement in trauma therapy:

"The exposure sessions were hard, but I really liked how my counselor walked me through them every time and made me feel safe. I really liked that my counselor was also Indigenous and understood our histories, our intergenerational trauma, everything that our community faced. So, seeing myself in the therapist also really helped establish that trust."



Lessons Learned

The COVID19 Pandemic

The COVID19 pandemic occurred while Story Medicine was recruiting clients and during client therapy. The pandemic sometimes made it harder for clients to stay connected and engaged, as when lockdowns started, we pivoted all clients to virtual appointments. Additionally, the stresses of the pandemic interfered with initiation and/or continuation of therapy for some clients, who were reluctant to engage, know that working through traumas, even with expert therapy, can be an additional stressor and sometimes result in the client feeling worse before they feel better.

The COVID19 pandemic is a traumatic stressor in itself, because of indirect stressors (e.g., COVID19 media coverage) and direct stressors like having contact with the virus, unemployment, isolation, loss of friends and family (7). While the COVID19 pandemic showed many of the strengths and resiliencies of Indigenous communities in Canada, for example the strengths of kinship ties and adaptations to cultural ceremonies and rituals, it also had more negative impacts for Indigenous peoples in Canada (8). In Canada, COVID19 highlighted the inadequacies that exist in the health care system for Indigenous populations because of colonialism, historical trauma, unfair policies and gaps in the current system (9).

Further, physical distancing and social isolation as a result of lockdown, contributed to an increase in mental health and social challenges like domestic violence, anxiety, inadequate housing, difficulty getting supplies like food, water, and cleaning products, and restrictions on social and cultural ceremonies and gatherings (9). Also, poor internet access in rural and remote communities made it harder to receive support from service workers and family and friends (9). One client in the study had to stop doing Story Medicine because they did not have good internet access.

Because of all the extra issues that happened from COVID, recruitment was put on hold from March 2020 – November 2021.

Distance And Geography

Indigenous clients do not trust and often do not go to mainstream health services like hospitals because they have experienced racism and discrimination in these places (10). While we were able to do Story Medicine with clients in areas outside of Toronto (e.g. Guelph, Kenora, and on-reserve) using Ontario Telemedicine Network (OTN) and Zoom, it was hard to change appointment times and to be flexible, due to scheduling systems and limited therapist hours.

Privacy And Childcare

COVID19 social restrictions meant that many clients were accessing therapy from home using zoom, where privacy and safe space also presented a challenge, especially for those with children and other family at home. Childcare and family care responsibilities made it harder for clients to schedule and keep appointments, especially when there was a lockdown and childcare was closed.

Lack Of Cultural Safety

Another barrier to doing online Story Medicine was the lack of trust in hospitals and clinics where clients had to go to use Ontario Telemedicine Network (OTN). For those clients who were comfortable going to hospitals or health centres to use OTN, we were able to provide transportation to and from appointments using trains and driving services for clients who did not have any other way to get to appointments.

Number Of Sessions

Clients found that the ten sessions were not enough and that they voiced a need for longer time sessions and also more sessions. The therapists did have some flexibility and at times pivot a session from narrative exposure to client when a client was experiencing a new serious and traumatizing issue, but clients told us that we should include these types of extra sessions in Story Medicine, not just add them in when the client was having a hard time.

Ongoing Challenging Life Events And/Or Traumas

Clients had ongoing challenging life events and traumas:

- Having complex PTSD
- Ongoing Indigenous colonial trauma and colonialism (e.g., racism)
- Poverty: 58.3% of clients told us that their health and well-being affected by financial hardship
- 41.7% clients told us that they struggled to have enough food more than once a month
- Clients had very high average adverse childhood experiences scores of 7.6 (SD=2.8); depression scores (PHQ) of 16.2 (5.5); anxiety scores (HAM-A) of 28.7 (14.0); and PTSD (PSSI-5) scores of 44.9 (29.3) at the beginning of treatment
- Most clients told us that their overall health and wellbeing had been affected by the **involvement of child protection** in their family, and that 58.3 % of clients had CPA involvement as children, and 33.3 % of clients with children had CPA involvement the care of one of their own children.
- Clients reported many symptoms including strong emotions, such as **anger and shame** (91.7 %), **numbing/dissociation** (75 %) and **difficulty sleeping** (75 %).
- They also report using **tension reducing behaviours** including eating (33.3 %), alcohol (16.7 %) and drug use (16.7 %).



Conclusions

Overall, Story Medicine worked well for most clients. Story Medicine should be looked at as "one tool in the Indigenous trauma toolkit" because it appears to work better for some clients more than others. Therefore, the therapist should really think about whether (and how) Story Medicine might work for their client. We learned that clients who had more complicated mental health needs and/or who also had ongoing traumatic life problems might do better with a non-exposure therapy that is focused on symptom management and stress reduction. We also learned that more sessions of Story Medicine would probably be more helpful with most clients.

One of the reasons that we liked Narrative Exposure Therapy (NET) as a potential therapy to adapt for Indigenous peoples was that NET is often delivered by peer counselors. However, we found during our trial of the adapted Story Medicine Narrative Exposure Therapy that *at this time we would not recommend that Story Medicine be delivered by peer counselors.* Instead, we recommend, given the complexity of the trauma and contexts experiences by FNIM clients, having access to skilled therapists who are culturally safe to deliver Story Medicine is best.

We do agree as a study team that Story Medicine is ready to be adapted using what we have learned so far and then tested with a bigger group of clients.

Policy Recommendations

There have already been many policy recommendations made to address MMIWG in the <u>Reclaiming Power and Place: The Final Report of the National Inquiry into Missing and Murdered Indigenous Women and Girls.</u>

These recommendations are focused specifically on next steps now that this pilot Story Medicine project has been completed.



Train more Story Medicine therapists

- Therapists would all be working with Indigenous clients
- Story Medicine is one tool in their toolbox



Do a larger Story Medicine Trial

- Lead another Story Medicine research project (or find another Indigenous organization who will)
- Include the newly trained therapists
- Find a new funding source



Provide information for First Nations individuals and organizations about Non-Insured Health Benefits and whether it will cover Story Medicine



Get Story Medicine Vetted as "Best Practice"



Present on Story Medicine at more conferences so that other people can learn about it (e.g., Canadian Psychological Association conference)



Partner with an Indigenous organization to continue providing Story Medicine



Encourage Story Medicine therapists to continue to offer and use Story Medicine therapy to future clients who could benefit from it.

Develop a Story Medicine manual so that other therapists can learn how to do it on their own



- Use Creative Commons copyright on it so that anyone can use, cannot make money off it, and they must acknowledge use of SM manual
- Distribute it for anyone to use with their Indigenous clients
- Provide training online at a small cost (or free)

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Appendix A: Story Medicine Advisory Council Terms Of Reference

STORY MEDICINE: PILOTING NARRATIVE EXPOSURE THERAPY TO SUPPORT TRAUMA-ENGAGED TESTIMONY AND HEALING FOR FAMILIES AS PART OF THE NATIONAL INQUIRY ON MISSING AND MURDERED INDIGENOUS WOMEN AND GIRLS

TERMS OF REFERENCE

Document: Story Medicine Advisory Council Terms of Reference Approval Authority: Story Medicine Advisory Council Date Document Approved: August 2, 2018

Mandatory Review date: Fall 2019

PREAMBLE

Story Medicine is a research project delivered by the Well Living House, St Michael's Hospital, Toronto and funded by the Keenan Foundation, St Michael's Hospital Foundation. The goal of the project is to demonstrate the effectiveness of tailored Indigenous Narrative Exposure Therapy intervention as a tool to support healing for families coping with the trauma of losing a family member and who may be a part of the National Inquiry on Missing and Murdered Indigenous Women and Girls. Core components of the intervention maintain the fidelity of NET as it is implemented with vulnerable populations, while Indigenous specific adaptation will enhance the synergy of NET with traditional Indigenous storytelling, counselling and healing practices.

PROJECT OBJECTIVES AND OUTCOMES

The story medicine project seeks to:

- 1. Build partnerships with families, the Ministry of the Attorney General and the advisory group.
- 2. Develop an Indigenized NET that maintains core components but optimizes alignment with Indigenous storytelling; counselling; and healing practices.
- 3. Determine the efficacy of the Indigenous-NET trauma treatment in a clinical trial that compares NET to a waitlist NET arm that acts as the control stream with a high level of scientific rigor.
- 4. Develop, evaluate, document and disseminate clinical treatment research findings and training to local Indigenous counsellors that will continue to benefit the Indigenous community by placing direct trauma training, knowledge translation activities and products directly in the hands of the Indigenous community, helping knowledge users and Indigenous partner clients to take more control over their lives.

ADVISORY COUNCIL

The advisory council will gather quarterly and advise on Story Medicine project logistics, recruitment and ethical issues, help mitigate any unintentional harms of the study, assure the work is of optimal benefit to the Indigenous community and to help share the results and enhance the uptake of the work.

PARTNERS

The council will be comprised of a family member of a MMIWG, Elder/Knowledge keeper, Health/Service providers, a representative from the Ministry of the Attorney General's office, and the research team members.

- · Carol Terry, Traditional Knowledge Keeper, Well Living House Grandparents Governance Board
- Carol Hopkins, Thunderbird Partnerships
- Magen Cywink, MMIWG Advocate and Family Member
- · Kimberley Orton, Midwife, Seventh Generation Midwives Toronto, Toronto Birth Centre
- Janet Smylie, Lead Network Investigator, Director, Well Living House
- · Tessa Colthoff, Project Investigator, Psychologist, Women's College hospital
- MMIWG Friend or Family member (TBD)

RESPONSIBILITIES

Advisory council members agree:

- To meet quarterly in person, by teleconference, or by videoconference over the project timeline (3 years). To share the responsibility for achieving the project goal of using Indigenous NET to promote healing among friends and family members of MMIWG.
- To promote the recruitment of clients who meet study eligibility requirements.
- To provide guidance on traditional teachings and protocol so as to practice Indigenous NET in a good way.
- To support with cultural translation.
- To offer expertise with respect to cultural safety and application of the therapeutic technique.
- To advise on how to ensure the work is of optimal benefit to Indigenous community member clients.

QUORUM

A quorum for the meetings of the advisory committee shall consist of one-half the members of the advisory committee present in person, by teleconference, or by videoconference. One member of the Story Medicine Research Team must be present.

Appendix B: Story Medicine Project Team



Janet Smylie, Lead Network Investigator, Director, Well Living House

Dr. Janet Smylie is a family physician and Indigenous health research scientist. A Métis woman, Dr. Smylie, acknowledges her family, teachers, and lodge. She holds a Tier 1 Canada Research Chair in Advancing Generative Health Services for Indigenous Populations in Canada and at St. Michael's hospital, Li Ka Shing Knowledge Institute where she directs the Well Living House Applied Research Centre (www.welllivinghouse.com) and is a staff Family and Community Medicine staff physician. She is a Professor in the Dalla Lana School of Public Health, and DFCM, Faculty of Medicine, University of Toronto. Dr. Smylie has practiced and taught family medicine in diverse Indigenous communities both urban and rural. She maintains a part-time clinical practice with Inner City Health Associates at Auduzhe Mino Nesewinong. Her applied research program is focused on actively addressing Indigenous health inequities by enhancing Indigenous led, high quality health information systems; disrupting anti-Indigenous racism in health services; and promoting Indigenous community health and wellbeing solutions. Dr. Smylie currently leads multiple research projects in partnership with First Nations, Inuit, and Métis communities/organizations. She has participated on multiple expert advisories. She was honoured with a National Aboriginal Achievement (Indspire) Award in Health in 2012 and is a fellow of the Canadian Academy of Health Sciences, the Royal Society of Canada, and the National Academy of Medicine.



Tessa Colthoff, Project Investigator, Psychologist, Women's College Hospital

Tessa Colthoff is a psychological associate who is a clinician with the Trauma Therapy Program at Women's College Hospital and works in private practice. Tessa holds a master's and post graduate degree in clinical psychology from the University of Amsterdam and is a registered psychologist and trauma therapist in the Netherlands. Tessa's clinical area of interest is working with adult survivors of childhood trauma, war, organized and systemic violence. She provides individual, group, and couple's therapy, is engaged in several research projects and supervises students and learners.



Nicole Muir, Project Investigator, Professor of Psychology, York University

Dr. Nicole Muir is a Métis researcher who is currently an Assistant Professor in Clinical Developmental Psychology at York University. She recently completed a Post-Doctoral Fellowship at Well Living House, an Indigenous research centre. Dr. Muir completed a master's degree in Clinical Child Psychology followed by a PhD in Forensic Psychology, both at Simon Fraser University. Within Indigenous youth populations living in cities, Dr. Muir's research focuses on colonialism, trauma and victimization, foster care involvement, justice system involvement, and violence risk assessment tools. Dr. Muir's overall aim is to achieve both scientific excellence and Indigenous community relevance by ensuring Indigenous community involvement from research conception to research dissemination.



Jessica Syrette, Research Coordinator, Social Worker, Well Living House

Jessica (she/her) is an Anishinaabekwe with European ancestry. Her father comes from Batchewana First Nation and her mother's family come from Ireland, Scotland and England. She was born in Tkaronto and has long considered this her home community.

Jessica completed her Master of Social Work at University of Toronto in the Indigenous Trauma and Resiliency program. She is a Registered Social Worker with the Ontario College of Social Workers and Social Service Workers. She is passionate about wellness in her community, with a focus on intergenerational trauma, development, and perinatal mental health. Jessica seeks to practice trauma-informed, culturally safe, and 2SLGBTQQIA+ friendly care, with the understanding that these require consistent attention, growth, and learning from her.Being a First Nations woman is central to who Jessica is as a person and as a practitioner. She endeavours to keep the Seven Grandfather Teachings at the heart of her work, and holds a deep respect for FNIM cultures and knowledge. She takes a holistic approach to healing, and uses the medicine wheel to bring together the mental, emotional, spiritual and physical aspects of wellness. Jessica's practice is rooted in trauma-based treatment, narrative therapy, and psychoeducation. Her collaborative approach integrates techniques from cognitive behavioural therapy, art therapy, mindfulness, and somatic therapy in hopes of offering support to folks on their healing journeys.



Genevieve Blais, Research Coordinator, Oshkabeewis, Well Living House

Genevieve (she/her) is Turtle Clan, First Nations with mixed European ancestry. Her mother is from Oneida Nation of the Thames and her father's family has mixed Irish and French ancestry. Genevieve completed her honors BSc at the University of Toronto and has worked in Indigenous Health research since 2014. Genevieve is currently the Research Program Manager at the Well Living House, a winner of several Indspire scholarship awards and Unity Health Toronto Community Partnership Award, awarded to an individual who consistently models exemplary community partnership practices and integration of the perspectives of community and people with lived expertise into their research. She also works closely with Traditional Healers and Elders as an Oshkabeewis in her community of Tkaronto.

Appendix C: Story Medicine Advisory Council



Meggie Cywink, MMIWG Advocate and Family Member

Nindizhiakaaz Meggie Cywink nindigoo ojibwemong Niigan E'maset kwe. Waabizheshi nindoodem. Nindoonjibaa Adikamegoshii-ziibiing. For over 30 years, Meggie has been a passionate and relentless advocate for the Missing and Murdered Indigenous Women and Girls, Trans, and 2-Spirit (MMIWGT2S+) persons. After the loss of four loved ones, she brings an authentic perspective, with the unyielding knowledge that the work of families is complex. She believes there will always be a need to seek truth and justice and understands the significance of trust-building with families. Meggie believes in the resiliency of community, the arduous work of supporting Families and Survivors from a family-led and community-driven continuum through land-based ceremony and is dedicated to the families in honouring the spirits of their loved ones. Meggie worked for the Ontario, Ministry of Attorney General – Indigenous Justice Division as Special Advisor for the Ontario Missing and Murdered Indigenous Women and Girls -Joint Inquiry team from 2016 – 2019. She liaised with Ontario families, and the provincial and federal governments in her role. She brought experience and perspective that served to inform the level of trauma and emphasized the need to continue to help families heal. She has turned her attention to the healing of families and finding a way to help them move beyond the grief and traumatic loss. She is a grassroots MMIWGT2S+ Family Member who is the owner of an independent First Nations business, Seven Directions Consulting. Meggie has been involved in various MMIWGT2S+ initiatives and projects including We Dance for Life www.wedanceforlife.com, spearheading numerous provincial healing gatherings, Shades of Our Sisters digital story and installation www.shadesofoursisters.com and the Circle of Aunties educational toolkit. She has also been engaged on a health advisory council to work with families in a therapeutic model designed to help families process traumatic experiences. She has spoken internationally on the MMIWGT2S+ platform. Meggie has a passion for genealogy and is currently, researching and authoring a book, "First Nations and All Our Relations", that traces the collective ancestry of the Anishnaabe people back to 1789, including the exodus from Michigan into Manitoulin Island. In addition to honouring this collective remembrance, the proceeds of the book will support the placement of permanent grave markers and the continued upkeep of First Nations cemeteries on Manitoulin Island. "I believe in the empowerment of youth to change to course of Indigenous rights and history. By giving them the tools to make informed decisions about their choices we are walking together to help our children, our future leaders."



Carol Terry, Traditional Knowledge Keeper, BA, Bed, Obishikokaang (Lac Suel)

Her parents: Mary Elsie Cromarty and John (Shabwaykeesic) Kenny raised the family on their traditional lands and waters of Lac Seul. Carol was birthed by a traditional midwife from the community. She attended Pelican Lake Residential School near Sioux Lookout, and Cecilia Jeffrey in Kenora. She is a graduate of Beaver Brae Secondary School, Kenora. As an adult learner, Carol has completed her BA through distance education from Lakehead University, and completed her Bachelor of Education degree from Queen's University and Seven Generations. Carol is a strong believer of life-long learning. In the health field, Carol has been employed as a Program Manager for Health Canada, and as a Health Director for two different tribal councils in Sioux Lookout. Together with her husband Tom, they raised three children: Cal, Kanina and Jesse. They are now proud grandparents to: Jaylynn, Miaka, Tevai, Dolor and Miali. Tom and Carol are delighted to have all their children and grandchildren living in Sioux Lookout. The Terry family is passionate about being out on the land. They continue to travel the many waterways of north western Ontario by canoe, and in the winter months, by dog teams.



Carol Hopkins, Thunderbird Partnerships

Carol Hopkins is the Chief Executive Officer of the Thunderbird Partnership Foundation (a division of the National Native Addictions Partnership Foundation) and is of the Lenape Nation at Moraviantown, ON. Carol was appointed as an Officer in the Order of Canada, 2018. In 2019, she received an honorary Doctor of Laws degree from Western University.

Carol has spent more than 25 years in the field of First Nations substance use and mental health. She holds both a Master of Social Work Degree from the University of Toronto and is 4th degree Midewiwin, a sacred Anishinabe medicine society where she is also Water Chief and leader. This society is te source of sacred Indigenous Knowledge which is then translated into accessible means to inform mental wellness of First Nations. This learning and development through Midewiwin is easily equivalent to a PhD in western based education systems.

Carol has throughout her career, made use of Indigenous knowledge in research, policy, practice-based evidence, teaching, and education, and in facilitating processes of decolonization specific to epistemic racism. She has cochaired national initiatives known for best practice in national policy review and development, resulting in the: First Nations Mental Wellness Continuum Framework (FNMWC), the Honouring Our Strengths: A Renewed Framework to Address Substance Use Issues Among First Nations in Canada, the Indigenous Wellness Framework, and the Native Wellness Assessment. Her leadership has been engaged within Health and Mental Health for First Nations, Provincial, Territorial, and Federal governments serving a number of expert advisory and task groups.