Journal of the Canadian Association of Gastroenterology, 2024, **7**, 255–260
https://doi.org/10.1093/jcag/gwad059
Advance access publication 27 December 2023
Original Article

Storytelling of Indigenous patient and family advocates engaged in patient-oriented research initiatives in the field of inflammatory bowel disease

Rhonda Sanderson[1], Linda Porter[2], Robert Porter[3], Colten Brass[4], Derek Jennings[5], Michelle Johnson-Jennings[6], Mustafa Andkhoie[7,8], Germain Bukassa-Kazadi[9], Sharyle Fowler[10], Jose Diego Marques Santos[11], Jessica Amankwah Osei[11], Carol-Lynne Quintin[12], Ulrich Teucher[13], Juan Nicolás Peña-Sánchez[11,*]

[1]James Smith Cree Nation, Saskatchewan, Canada
[2]One Arrow First Nation, Saskatchewan, Canada
[3]York Factory First Nation, Manitoba, Canada
[4]Muskoday First Nation, Saskatchewan, Canada
[5]School of Public Health, University of Washington, USA
[6]School of Social Work, University of Washington, USA
[7]School of Public Health, University Saskatchewan, Canada
[8]Health Surveillance and Assessment Unit Service, Department of Indigenous Services Canada
[9]Independent researcher
[10]Division of Gastroenterology, Department of Medicine, University Saskatchewan, Canada
[11]Department of Community Health and Epidemiology, University Saskatchewan, Canada
[12]Crohn's and Colitis Canada, Saskatchewan, Canada
[13]Department of Psychology and Health Studies, College of Arts & Science, University of Saskatchewan, Canada

[*]Corresponding author: Juan Nicolás Peña-Sánchez, MD, MPH, PhD, Room 3232—E-Wing Health Sciences, 104 Clinic Place, Saskatoon SK S7N5E5, Canada (juan.nicolas.ps@usask.ca).

Abstract

Background and aim: The history of colonization and its ongoing impact poses significant health disparities among Indigenous communities. We aimed to centre the voices and stories of Indigenous patients and family advocates (IPFAs—Indigenous patients living with inflammatory bowel disease [IBD] and family members of Indigenous individuals with IBD) engaged in patient-oriented research projects and who are part of the IBD among Indigenous Peoples Research Team (IBD-IPRT).

Methods: IPFAs and Indigenous and non-Indigenous researchers of the IBD-IPRT followed a storytelling research methodology to let IPFAs share their stories as research team members. Four IPFAs documented their experiences as IBD patients, advocates, and research partners. The stories were analyzed for themes. The identified themes were collaboratively verified with the IPFAs.

Results: The full stories shared by the IPFAs were transcribed and presented in this paper. Following a background analysis of themes in the 4 narratives, we were also able to identify 4 key themes that could be relevant to improving patient-oriented research initiatives: (1) health promotion, (2) leadership and voice, (3) community engagement, and (4) disease awareness and access to care. Trust building, strong relationships, and effective partnerships are core components for conducting patient-oriented research with Indigenous community members.

Conclusions: Indigenous patient engagement in health research is crucial to ensure that lived experiences, knowledge, and cultural values are adequately adopted to improve research outcomes. Centering IPFAs in IBD research can promote cultural awareness and actionable recommendations to improve health outcomes for individuals with IBD and their families and caregivers.

Key words: Indigenous peoples; storytelling; patient-oriented research; inflammatory bowel disease; Indigenous patient and family partners.

Background

Indigenous medical research has a history of unethical research and lack of consultation of communities, with colonialism being argued as a large contributor to Indigenous peoples' ill health and a social determinant of health.[1,2] Although, as Walters et al.[3] argued, "…we are now in a health research era in which Indigenous voices are rising up and uniting to advocate for the design and development of culturally grounded research." For Indigenous communities' voices to be centred within research, their stories must be told and heard by Indigenous and non-Indigenous researchers and knowledge users.

Inflammatory bowel disease (IBD) is a chronic gastrointestinal condition with significant disease-related complications that has been broadly studied in the general population. Indigenous individuals living with IBD shared with Indigenous and non-Indigenous researchers their lived experiences and concerns regarding the lack of evidence and awareness of this condition among Indigenous peoples.[4] Consequently, a patient-oriented research (POR) initiative in the field of IBD was initiated in Saskatchewan, Canada, engaging a multidisciplinary team to advocate for better healthcare and well-being for Indigenous peoples with IBD,[4,5] the *IBD Among Indigenous Peoples Research Team* (IBD-IPRT, https://research-groupstest.usask.ca/ibd-among-indigenous-peoples/index.php). The research team is composed of 2 Indigenous individuals living with IBD, 2 family members of Indigenous persons with IBD, university-based researchers (some of them Indigenous), and knowledge users, including a healthcare provider, a representative of a community-based patient organization, and a government-based public health practitioner.

Despite the wide range of IBD research in the general population, there was a gap in research *about* and *with* IBD among Indigenous Peoples in Canada, including First Nations, Inuit, and Métis peoples. Canada has one of the highest rates of IBD worldwide.[6,7] Previous research indicated that Indigenous individuals were less likely to have IBD than individuals from the general population.[8–10] Recently, the IBD-IPRT reported that in Saskatchewan the IBD prevalence among First Nations individuals has been increasing since 1999, while the incidence rates of IBD have remained relatively stable.[5] Furthermore, the IBD-IPRT found that First Nations with IBD were less likely to claim IBD medications and had a higher risk of hospitalizations than the general population with IBD.[11]

The Indigenous patient and family advocates (IPFAs—Indigenous patients living with IBD and family members who advocate for Indigenous persons with IBD) who are part of the IBD-IPRT have been active and central members of the team and the applied research framework, having voice and vote in each of the research stages and decisions of the project,[5] in the team's spirit of consensus so that no Indigenous voice is ever overruled. This paper aims to centre the voices and stories of the IPFAs of the IBD-IPRT examining the commonalities in their stories as community-based researchers.

Methods

Indigenous storytelling has been explored as a decolonizing research method that could effectively represent Indigenous knowledge systems and worldviews.[12–14] Indigenous storytelling is a traditional way of knowing for Indigenous peoples, grounding itself in a unique history and trajectory.[15] This Indigenous way of knowing encompasses the lived values grounding Indigenous governance and regeneration, which have particular importance for nurturing and teaching Indigenous traditions.[16] Indigenous narratives can describe acts of resistance and colonial injustices and can voice multiple meanings and truths, contributing to knowledge creation.[15] Indigenous storytelling encompasses Indigenous ontologies and epistemologies, in which knowledge is embodied and timeless.[12–15] Indigenous story work formed the basis of our research framework and guided our analysis including respect, responsibility, reciprocity, reverence, holism, interrelatedness, and synergy.[12–14]

The 4 IPFAs of the IBD-IPRT decided to voluntarily share their stories as research team members. Two university-based researchers asked the IPFA how they preferred to share their stories (eg, in person meeting, telephone, or as a write up). The researchers attempted to create a friendly environment in which the Indigenous stories were completely guided by the IPFA. IPFAs were asked and agreed to tell their stories as members of the IBD-IPRT without interruptions. This non-interference was done to highlight the IPFA's role as protagonists of their own stories. This work did not seek ethics approval as this initiative presents the willingness and leadership of 4 IPFAs to tell their own stories as community members doing research.

Three IPFAs wrote-up their stories themselves and one of them preferred to tell the story in person and be recorded. This recoding was transcribed and revised by a university-based research team member. The full 4 narratives were transcribed within this article. IPFAs had the opportunity to edit their storytelling and determine what they wished to share. Subsequently, the 4 stories were analyzed for themes guided by the principles outlined by Jo-Ann Archibald for Indigenous storytelling.[12,13] According to this Indigenous scholar, 7 principles comprise Indigenous "Storywork" (the term "work" signalling the importance and seriousness of making meaning through stories): respect, responsibility, reverence, reciprocity, holism, interrelatedness, and synergy. The first 4 Rs involve both teller and listener/researcher in the communication; the other 3 principles refer to the learning process since Indigenous stories ("gifts", not "data") are always a call for transformative learning. Each of the 7 terms has its own explanation. For example, the actions of interrelatedness and synergy formed by the storyteller, the story, the listener, and the context in which the story is used, make for effective storywork. In all these ways, Indigenous storywork differs substantially from Western qualitative research methods.[12,13] The identified themes were collaboratively verified with the IPFAs. In doing so, we have supported their voices and their roles as coauthors of this article.

Results

Rhonda's story

"I feel very honoured to be part of the IBD research group as one of the Indigenous voices. We do not have a strong voice that I could advocate for young people who are being diagnosed with IBD so that they do not have a hard time getting the services they need. The project and research group that I am involved with has given me a voice to educate all the people involved. They did not know some of the stereotypes in the information that is said to us. They were not aware that as soon as our older health cards were issued, although it is not so much an issue now, the health cards had the letter R on it, stating that I was a registered Indian. This would tell the healthcare community that I was Indigenous, and this little R impacted the 'type' of services received. I received the services, whether it was 'great or not so great,' but the 'R' allowed the medical community to know that I was Indigenous.

Being part of this research group has helped me educate people who do not realize that as Indigenous people, we are not very vocal. We tend just to stand back and let things happen, and this project has allowed me to say: 'No more, we need to stand up for ourselves!.' We need to say you cannot treat us 'this way.' We need to advocate for people who will be diagnosed with IBD so that they will have an easier time with the diagnosis and access to different clinics, specialties, and doctors. All the research seeking for IBD care I have done for myself, including the discovery of the IBD clinic at the Saskatchewan Royal University Hospital by myself.

On the Saskatoon Health web page, I found the IBD clinic. I was like, 'Wow,' but nobody ever made notice or gave me the information about this type of clinic. I was not aware that this type of care was available to me. It was such a unique experience that I received from the IBD clinic. Through the IBD Clinic, I became involved with this IBD research group. I was so honoured when the researcher had approached me and asked me if I was interested in participating. At first, I was a little reluctant because I was not sure what was expected of me or how my voice was going to be utilized. But I feel so honoured that the team takes everything that I say. They take it, and they hold it with great honour. They get educated by my unique experience with the healthcare system as an Indigenous person. It is so rewarding that nobody would have to, or hopefully, nobody will have to face the same challenges I faced being diagnosed with IBD. I feel that the research team is opening a whole lot of doors. I am very proud that I am one of the Indigenous voices in this project, that we are being listened to it, and that they do take everything that we say. I am very proud that the stories that we share and the information that we share with the group hold it up to the highest esteem. I feel very honoured that I am listened to.

I was very pleased to have been chosen to be the Indigenous voice to our presentation in Halifax, Nova Scotia in 2019 (oral presentation at the Canadian Association for Health Services and Policy Research conference). It was a unique experience to be there and to present our project and to share my journey with IBD to all these educated people—they listened to me. I really felt listened to, and I really felt appreciated. It was such a unique experience that I had the opportunity to share my journey. It was great to feel listened to and to have been given a chance to share my experience with IBD as an Indigenous person. This experience is important because, for so long, our people have been silenced. But it is so nice to have finally been given a voice and a platform to do positive change for Indigenous people."

Linda's story

"My name is Linda Porter, and I became involved with the IBD research group as a Patient Advisor through the Gutsy Walk (a walk organized by Crohn's and Colitis Canada across provinces to raise funds and support of those impacted by IBD) in Saskatoon. Our daughter Lisa John suffered and lost her life to Crohn's disease. Our contact Caroline Quinn introduced me to Juan-Nicolás (one of the principal investigators of the IBD-IPRT), and he asked if we (my husband and I) wanted to join the research group. I was a little intimidated when I joined the group as it was very diverse, and the group members had different accents and I found that I had trouble with understanding everyone at first. Plus, they all sometimes spoke in jargon that was not very easy to understand. However, as time progressed, I became more comfortable with the group. I found that my opinion matters, and I wanted people to know what obstacles we encountered at the hospitals and through the healthcare system.

I would like to share how the group has gotten comfortable with each other as time passed. On a trip to Regina with our research team, we were on a bus to a conference and we as a group sat together at the back of the bus. I had bought a pack of cards and asked the group to play a childhood card game called 'crazy-eights'. The students and professors we were with from the group had never played the game and we had so much fun with this childhood game. I have since become more comfortable with my group and able to be more open in the group.

I feel that this group is very diverse. We have many different cultures in our group and very opinionated, which is great. They are all willing to listen to us patient advisors and value our input. I am really looking forward to continuing with the group and finding the numbers of IBD in our province of Saskatchewan.

My daughter Lisa was a big part of my life and when we joined the Gutsy Walk when she was alive, she would join us, and we had one of the biggest groups at the walk. After her passing, we still walk in her memory, and we all have t-shirts in pink (which was her favourite colour). I believe that we as her parents have a wealth of knowledge and the experience that we would like to share if it helps in this project."

Robert's story

"I am Robert Porter and I am very proud to be an Indigenous Family Patient Advisor. This role was unknown to me a few years ago, but after struggling along with my youngest daughter's fight for several years with Crohn's disease, I was approached to consider joining a group of people that were looking into the field of IBD and our Aboriginal peoples. After considering, I was intrigued and believed this could serve as an avenue for me to continue my girl's story and help educate others with my family's experiences.

After meeting our group for the first time, I noticed how diverse our group's individual cultures and the range of personalities were. But I soon realized that these differences worked well together and found myself eagerly looking forward to future meetings where we would exchange our thoughts on how our project should be steered.

Having developed an appetite for getting the word out there about our project, the next step was meeting others and exposing our findings to those who would like to listen.

For me, this has been the most satisfying portion, and I am hoping that we can get into our Aboriginal communities to expose this IBD for the cruel disease that it is.

Being a researcher has given me a newfound desire to further the fight to get IBD information out to the communities and the hope that we can help improve the quality of life for individuals living with IBD, which is something my late daughter yearned for. To this I will be grateful to our group as it will afford me the venue to continue the desires of my daughter to make IBD suffering a thing of the past."

Colten's story

"I have been diagnosed with Crohn´s disease. I enjoy playing the guitar and working with computers inside and out. In 2018, I was asked to be part of the IBD among Indigenous people project, and it has been a great experience. Being part of something like this was an excellent opportunity to make a positive impact on the Indigenous communities everywhere.

As patient/family advisors, we have been contributing, overseeing, and deciding on all aspects of the project! The rest of the research team has made it very clear that our input and say is essential for the group to be able to move forward. The research team usually has monthly meetings and is very active. Our group is passionate and forward-thinking. The family and patient advisors including myself get into contact with Tribal Councils. Engaging with my community has been excellent. I have the opportunity to be engaged and active.

I have been able to travel with some of the members of the team to present our research. There are days I would go to Saskatoon and Regina and days I travel outside the province. It's been great so far, and I hope this project will develop and produce the results it needs. It's been a great experience so far!"

Common story themes

The 4 IPFA who are part of the IBD-IPRT documented their experience as IBD patients, advocates, and researchers in a patient-oriented project.

For those of us who are non-Indigenous members of the IBD-IPRT, it has been heartbreaking to read impressions from our Indigenous team members that should go without saying, namely that each one of them felt honoured to be heard, listened to, and respected in our group, thereby revealing the depths of the colonializing disrespect that Indigenous peoples in these, their lands, had to suffer for much too long and are still suffering. While IPFAs feel honoured to be considered members of the research team, the non-Indigenous team members are the ones deeply honoured with the contributions and gratitude of our Indigenous colleagues. Their gratitude provides us with the urgent necessity to live up to their trust in us and do better.

We read in our colleagues' stories that all of this did not come easy at first: in the way, there was a colonial history of discrimination where Indigenous peoples were identified as "R" (registered Indian) in their health cards, for easy categorization by Western healthcare services, and targets of Western stereotyping. There was reluctance at first to participate in research, over concerns how their voice would be "utilized" in the research, betraying their (well-founded) past experiences that they would have no say in the research.

Another comment makes clear that we still need to communicate our research better to each other without the use of jargon; although, it may be difficult to share statistical analysis without resorting to specialist language. On the other hand, we may have been able to signal that we were not using statistical results to universalize our findings over the heads of our Indigenous experts but had their local Indigenous knowledges foremost on our minds. Our shared journey on a bus did indeed serve as an ice breaker where we could unreservedly enjoy hilarity and laughter and connect on primary human levels.

It may also speak to our research team that we represent a broad cultural spectrum, with members of the research team from the global south as well as the global north, and a sea of accents as we used English as the language where we could all connect. Our different, international cultural backgrounds, our diversity, may in some ways have well been functioning as a leveler of sorts where it was clear that the non-Indigenous team members from all over the world are visitors to these lands on which our Indigenous research partners are at home.

Overall, the stories of our Indigenous research partners reveal confidence that they have important knowledge to contribute to the understanding of Indigenous IBD that non-Indigenous researchers clearly lack; they have an overwhelming sense of generosity, of wanting to share their experiences for the betterment of other Indigenous peoples with IBD, and for the improvement of our colonial healthcare system. However, we must not forget that this generosity is grounded in the outrageous pains of suffering from IBD, by our Indigenous research team members, or by helplessly witnessing a family member, or own children, passing away from, as one of our members named it, this cruel disease. For these team members, their willingness to share their experiences and knowledge can be grounded in the wish to memorialize their family member, "to continue my girl's story" into the future.

Following this background analysis of themes in the 4 narratives, we were also able to identify in more formal ways 4 key themes that could be relevant to improving POR initiatives: (1) health promotion, (2) leadership and voice, (3) community engagement, and (4) disease awareness and access to care.

The 4 IPFAs described the importance of health promotion and leadership in their community. Health promotion around IBD was seen to be central among IPFAs. Through effective educational strategies, individuals living with IBD could be empowered to work in partnership with healthcare providers by taking an active role in the management of their health to enhance their quality of life. According to the IPFAs, the notion of health promotion should be consistent with the beliefs, worldviews and values of the community members involved in the research. The leadership and voices of individuals with lived experience could support the development of community-centred holistic interventions to improve healthcare access and wellbeing of Indigenous peoples. Regarding community engagement and disease awareness and access to care themes, Indigenous-led effective knowledge translation activities that focus on IBD disease awareness and access to care (while preserving Indigenous ways of knowing) should be prioritized in educating IBD patients, community members, healthcare providers, and family members of Individuals with IBD. All these interconnected themes highlight the importance of patients as researchers and the need to create awareness of POR initiative topics.

Discussion

In this paper, the IPFAs of the IBD-IPRT documented their experiences as IBD patients, advocates, and researchers in a POR project. The research team followed the story work principles of respect, responsibility, reciprocity, reverence, holism, interrelatedness, and synergy for this paper. The stories were presented in entirety to ensure that proper reverence was given and interrelatedness between each was considered. These 4 stories highlight the importance of building relationships with Indigenous peoples when conducting POR initiatives. For centuries, colonial research has not centred on the voices of the communities affected.[17,18] In doing so, Indigenous communities were often left with research that did not meet their needs, nor contributed effectively to health outcomes and, even worse, created harm.[17] Forming strong research partnerships and including Indigenous persons through all stages of research, especially in sharing power and building trust, is needed to improve health equity.[19]

The Truth and Reconciliation Commission calls, in article 19, "upon the federal government, in consultation with Aboriginal peoples, to establish measurable goals to identify and close the gaps in health outcomes between Aboriginal and non-Aboriginal communities, and to publish annual progress reports and assess long-term trends".[20] However, neither the truth nor the reconciliation of health inequity can be achieved without forming equitable partnerships. The IBD-IPRT believes that those experiential narratives of IPFAs are central to highlighting the need for us to reflect, learn, and build. As a team, we learned that listening and respecting voices are important for the relationship to progress. We further learned that the IPFAs want more than to simply guide the research design. They value and seek to develop interventions and accept leadership roles. As we seek to move IBD research forward among Indigenous peoples, it is imperative to continue to listen and value voices of IPFAs. While POR promotes engagement of patients and families in research,[21] decolonized POR should center Indigenous community voices, knowledge, and experiences in the research process. By working together with Indigenous patients and community members to co-develop, co-design, and co-conduct research, research could move forward from POR towards decolonized POR initiatives that have IPFAs at its core.

Conclusions

This paper explored lived experience of IPFAs as researchers in a POR initiative using storytelling. Indigenous patient engagement in health research is crucial to ensure patients' personal and lived experiences, knowledge, and cultural values are adequately adopted to improve the outcome of the research study. We presented the importance to engage IPFAs in health research which is achievable by building trust, strong relationships, and effective partnerships. Centering IPFAs in IBD health research can promote cultural awareness and actionable recommendations that lead to improved health outcomes for individuals living with IBD and their families and caregivers.

Acknowledgments

We acknowledge the land on which the members of the IBD among Indigenous Peoples Research Team live and work. We are on Treaty 6 and 4 Territories and the Homeland of the Métis. We pay respect to the First Nations and Métis ancestors of this land and reaffirm our relationship with one another. We also want to show our appreciation to the communities of the Indigenous patient and family advocates: James Smith Cree Nation, One Arrow First Nation, York Factory First Nation, and Muskoday First Nation. We also thank the College of Medicine of the University of Saskatchewan, the Saskatchewan Health Research Foundation, and the Saskatchewan Centre for Patient-Oriented Research for supporting our work.

Author Contributions

R.S., L.P., R.P., C.B., D.J., M.J.J., J.A.O., J.D.M.S., S.F., U.T., and J.N.P.S. contributed to the study design, completed the data analysis, interpreted the results, and drafted the manuscript. R.S., L.P., R.P., C.B., J.A.O., J.D.M.S. collected the data. All the authors initiated this study, critically revised the study for important intellectual content, contributed to data interpretation, and revised and approved the final manuscript.

Funding

This work was supported by the Saskatchewan Health Research Foundation and the Saskatchewan Centre for Patient-Oriented Research Sprout Grant award. This research project also received funding from the College of Medicine Research Award from the University of Saskatchewan. The funding agencies had no role in the study or the preparation of the manuscript for publication.

Conflict of Interest

S.F. has received honoraria for speaking or consultancy from AbbVie, Amgen, Janssen, Pendopharm, Pfizer, Sandoz, Takeda, and Eli Lilly. The other authors declare no conflict of interest.

Data Availability

All data was presented in this article. There are no further data associated with this article.

References

1. Czyzewski K. Colonialism as a broader social determinant of health. *Int. Indig. Policy J.* 2011;2(1):1–14. https://doi.org/10.18584/iipj.2011.2.1.5
2. Mundel E, Chapman GE. A decolonizing approach to health promotion in Canada: the case of the urban aboriginal community kitchen garden project. *Health Promot Int.* 2010;25(2):166–173. https://doi.org/10.1093/heapro/daq016
3. Walters KL, Johnson-Jennings M, Stroud S, et al. Growing from our roots: strategies for developing culturally grounded health promotion interventions in American Indian, Alaska Native, and Native Hawaiian communities. *Prev Sci.* 2020;21(Suppl 1):54–64. https://doi.org/10.1007/s11121-018-0952-z
4. Peña-Sanchez JN, Osei JA, Teucher U, Tremblay M, Fowler S; IBD among Indigenous Peoples Research team (IBD-IPRT). Working with Indigenous community and patient partners is essential to advance gastroenterology and hepatology research: perspectives from Canada. *Clin Gastroenterol Hepatol.* 2023;21(12):2993–2998. https://doi.org/10.1016/j.cgh.2023.08.005
5. Peña-Sánchez JN, Osei JA, Marques Santos JD, et al. Increasing prevalence and stable incidence rates of inflammatory bowel disease among first nations: population-based evidence from a western Canadian province. *Inflamm Bowel Dis.* 2022;28(4):514–522. https://doi.org/10.1093/ibd/izab096
6. Coward S, Clement F, Benchimol EI, et al. Past and future burden of inflammatory bowel diseases based on modeling of population-based data. *Gastroenterology.* 2019;156(5):1345–1353.e4. https://doi.org/10.1053/j.gastro.2019.01.002
7. Ng SC, Shi HY, Hamidi N, et al. Worldwide incidence and prevalence of inflammatory bowel disease in the 21st century: a systematic review of population-based studies. *Lancet.* 2017;390(10114):2769–2778. https://doi.org/10.1016/s0140-6736(17)32448-0
8. Green C, Elliott L, Beaudoin C, Bernstein CN. A population-based ecologic study of inflammatory bowel disease: searching for etiologic clues. *Am J Epidemiol.* 2006;164(7):615–23; discussion 624. https://doi.org/10.1093/aje/kwj260
9. Leach ST, Day AS, Moore D, Lemberg DA. Low rate of inflammatory bowel disease in the Australian indigenous paediatric

population. *J Paediatr Child Health*. 2014;50(4):328–329. https://doi.org/10.1111/jpc.12535
10. Murdoch TB, Bernstein CN, El-Gabalawy H, et al. Prevalence of genetic variants associated with inflammatory bowel disease in a healthy First Nations cohort. *CMAJ*. 2012;184(8):E435–E441. https://doi.org/10.1503/cmaj.110613
11. Santos JD, Fowler S, Jennings D, et al. Health care utilization differences between First Nations people and the general population with inflammatory bowel disease: a retrospective cohort study from Saskatchewan, Canada. *Canad Med Associat Open Access J*. 2022;10(4):E964–E970. https://doi.org/10.9778/cmajo.20220118
12. Archibald JA, Parent A. Hands back, hands forward for indigenous storywork as methodology. In Windchief S, San Pedro T, editors. *Applying Indigenous Research Methods: storying with peoples and communities*. Routledge; 2019: 3–20.
13. Archibald JA. *An Indigenous Storywork Methodology. Handbook of the Arts in Qualitative Research: Perspectives, Methodologies, Examples, and Issues*. 2008:371–93.
14. Smith LT. *Decolonizing Research: Indigenous Storywork as Methodology*. Bloomsbury Publishing; 2019.
15. Caxaj CS. Indigenous storytelling and participatory action research: allies toward decolonization? Reflections from the peoples' international health tribunal. *Glob. Qual. Nurs. Res*. 2015;2:2333393615580764. https://doi.org/10.1177/2333393615580764
16. Corntassel J. Chaw-win-is, T'lakwadzi. Indigenous Storytelling, Truth-telling and Community Approaches to Reconciliation. *English Studies in Canada*. 2009; 35(1):137-159.
17. Smith, LT. *Decolonizing Methodologies: Research and Indigenous Peoples*. Zed Books Ltd; 1999.
18. Wallerstein N, Duran B. Community-based participatory research contributions to intervention research: the intersection of science and practice to improve health equity. *Am J Public Health*. 2010;100(Suppl 1):S40–S46. https://doi.org/10.2105/AJPH.2009.184036
19. Christopher S, Saha R, Lachapelle P, et al. Applying indigenous community-based participatory research principles to partnership development in health disparities research. *Fam Community Health*. 2011;34(3):246–255. https://doi.org/10.1097/FCH.0b013e318219606f
20. Truth and Reconciliation Commission of Canada. Truth and Reconciliation Commission of Canada: calls to action. Winnipeg, MB: Truth and Reconciliation Commission of Canada; 2015. Available at: https://ehprnh2mwo3.exactdn.com/wp-content/uploads/2021/01/Calls_to_Action_English2.pdf (Accessed June 7, 2023).
21. Frisch N, Atherton P, Doyle-Waters MM, et al. Patient-oriented research competencies in health (PORCH) for researchers, patients, healthcare providers, and decision-makers: results of a scoping review. *Res Involv Engagem*. 2020;6(4):1–14. https://doi.org/10.1186/s40900-020-0180-0