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Deficit-Based Indigenous Health Research and the Stereotyping of Indigenous Peoples

Sarah Louise Hyett, Chelsea Gabel, Stacey Marjerrison et Lisa Schwartz

Résumé de l'article

La recherche en santé a tendance à être basée sur les déficits ; en tant que chercheurs, généralement nous quantifions ou qualifions l'absence de marqueurs de santé ou la présence d'une maladie. Cela peut créer un récit ayant des effets d'une grande portée pour les communautés déjà victimes de stigmatisation. Dans le contexte de la recherche en santé autochtone, un discours basé sur les déficits peut contribuer aux stéréotypes et à la marginalisation des peuples autochtones dans une société élargie. C'est particulièrement vrai lorsque les chercheurs ne parviennent pas à explorer les racines des déficits de santé, à savoir la colonisation, l'occidentalisation et les traumatismes intergénérationnels, au risque de confondre des problèmes de santé complexes avec des caractéristiques autochtones inhérentes. Dans cet article, nous explorons l'incompatibilité de la recherche basée sur les déficits avec les principes de plusieurs cadres éthiques, y compris le chapitre 9 de l'Énoncé de politique des trois Conseils (EPTC2), les principes PCAP® (propriété, contrôle, accès, possession), la Stratégie nationale sur la recherche inuite Inuit Tapiriit Kanatami et les principes de la Coalition canadienne pour la recherche en santé mondiale (CCRSM). En outre, nous nous appuyons sur des cas de recherche basée sur les déficits et le stéréotypage dans le domaine des soins de santé, dans le but d'identifier leur lien avec l'injustice épistémique et d'explorer des approches alternatives.

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Sarah Hyett[1,2], Chelsea Gabel[3,4], Stacey Marjerrison[5,6], Lisa Schwartz[1,7,8]

Résumé

La recherche en santé a tendance à être basée sur les déficits ; en tant que chercheurs, généralement nous quantifions ou qualifions l'absence de marqueurs de santé ou la présence d'une maladie. Cela peut créer un récit ayant des effets d'une grande portée pour les communautés déjà victimes de stigmatisation. Dans le contexte de la recherche en santé autochtone, un discours basé sur les déficits peut contribuer aux stéréotypes et à la marginalisation des peuples autochtones dans une société élargie. C'est particulièrement vrai lorsque les chercheurs ne parviennent pas à explorer les racines des déficits de santé, à savoir la colonisation, l'occidentalisation et les traumatismes intergénérationnels, au risque de confondre des problèmes de santé complexes avec des caractéristiques autochtones inhérentes. Dans cet article, nous explorons l'incompatibilité de la recherche basée sur les déficits avec les principes de plusieurs cadres éthiques, y compris le chapitre 9 de l'Énoncé de politique des trois Conseils (EPTC2), les principes PCAP® (propriété, contrôle, accès, possession), la Stratégie nationale sur la recherche inuite Inuit Tapiriit Kanatami et les principes de la Coalition canadienne pour la recherche en santé mondiale (CCRSM). En outre, nous nous appuyons sur des cas de recherche basée sur les déficits et le stéréotypage dans le domaine des soins de santé, dans le but d'identifier leur lien avec l'injustice épistémique et d'explorer des approches alternatives.

Abstract

Health research tends to be deficit-based by nature; as researchers we typically quantify or qualify absence of health markers or presence of illness. This can create a narrative with far reaching effects for communities already subject to stigmatization. In the context of Indigenous health research, a deficit-based discourse has the potential to contribute to stereotyping and marginalization of Indigenous Peoples in wider society. This is especially true when researchers fail to explore the roots of health deficits, namely colonization, Westernization, and intergenerational trauma, risking conflation of complex health challenges with inherent Indigenous characteristics. In this paper we explore the incompatibility of deficit-based research with principles from several ethical frameworks including the Tri-Council Policy Statement (TCPS2) Chapter 9, OCAP® (ownership, control, access, possession), Inuit Tapiriit Kanatami National Inuit Strategy on Research, and Canadian Coalition for Global Health Research (CCGHR) Principles for Global Health Research. Additionally we draw upon cases of deficit-based research and stereotyping in healthcare, in order to identify how this relates to epistemic injustice and explore alternative approaches.

Mots-clés

recherche autochtone, peuples autochtones, recherche axée sur les déficits, recherche axée sur les forces, recherche en santé, stigmatisation, éthique

Keywords

Indigenous research**,** Indigenous Peoples, deficit-based research, strength-based research, health research, stigmatization, ethics

Introduction

Research is responsible for many of the improvements in human health. Where disparities in health outcomes exist for certain groups of people, research can help to identify where systems are failing to serve these groups. However, historically Indigenous Peoples have been research subjects rather than participants; they have been subjected to unethical experiments, misrepresented in academic literature, and have had their knowledge exploited [1-3]. As Indigenous Peoples increasingly assert self-determination and control in research with their communities, Indigenous-led, collaborative research has the potential to enhance transformative changes in the health status of Indigenous Peoples [4]. To date, some communities have organized their own research and ethics processes – the Manitoulin Anishinaabek Research Review Committee (MARRC), and the Six Nations Research Ethics Committee, for example [5-7]. These community-based policies and processes can help ensure researcher priorities align with community goals, concerns and cultural norms, particularly given the diversity of Indigenous communities in Canada [7], which university and hospital research ethics boards are not necessarily positioned to understand. Furthermore, Indigenous scholars are conducting research using their own methods and methodologies [8-10], which present an avenue to the production of knowledge that is meaningful in Indigenous contexts, created by and for Indigenous Peoples.

Presently, ethical policy in Canada outlines the importance of free, prior, and informed consent for both Indigenous and non-Indigenous research participants [11]. Indigenous Peoples in Canada have some additional protections through the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2) that provides guidance on Research Involving the First Nations, Inuit and Métis People of Canada [3]. The TCPS2 chapter on Indigenous research was established as national policy in 2010 and was largely based on the prior 2007 guidelines, developed with wide Indigenous community consultation and published by the Canadian Institutes of Health Research (CIHR) [3,12]. However, the previous CIHR guidelines were specific to health research with Indigenous Peoples, as opposed to Indigenous research in general. Having these separate guidelines specific to Indigenous health research strengthened the ethics process in many ways [13]. All institutions that are eligible to administer and receive funding from the three federal funding research agencies in Canada must adhere to the TCPS2 guidelines [11]. Some researchers additionally align themselves with other frameworks such as *OCAP®* (ownership, control, access and possession) principles, the *Royal Commission on Aboriginal Peoples statement on research ethics*, *Assembly of First Nations: First Nations Ethics Guide on Research and Aboriginal Traditional Knowledge*, *First Nations Regional Longitudinal Health Survey: Code of Research Ethics*, *CIHR Guidelines for Health Research Involving Aboriginal People*, and *Inuit Tapiriit Kanatami: National Inuit Strategy on Research* among others [12,14-19]. Different frameworks may be appropriate for different projects, and in some instances, are more comprehensive than the TCPS2 guidelines [14].

In addition, the Canadian Coalition for Global Health Research (CCGHR) *Principles for Global Health Research* (Figure 1) [20], hold relevancy for Indigenous health research. CCGHR principles are based on a number of works including the aforementioned CIHR guidelines [12,20].

Figure 1: Canadian Coalition for Global Health Research - Principles for Global Health Research
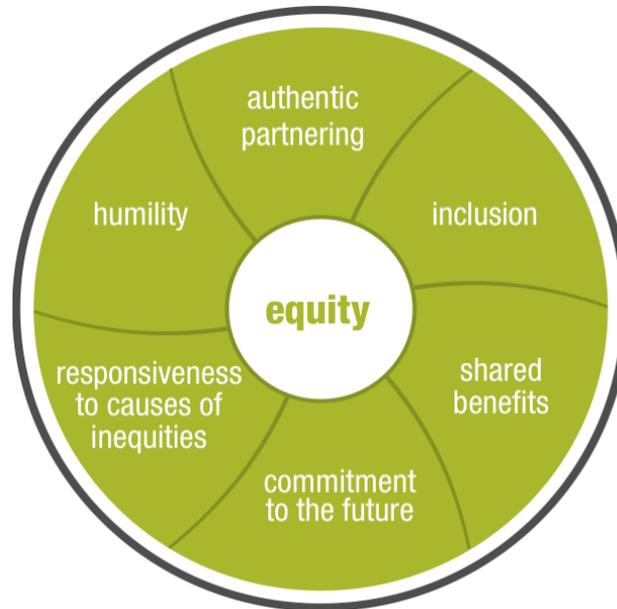
While ethical guidelines can assist with the conduct of research, even well-intentioned health research can sometimes have unintended consequences. Deficit-based research, which by its nature highlights poorer health outcomes in one group as compared to another, can perpetuate deficit-based narratives that contribute to stigmatization and stereotyping [21]. Taken alone, these findings can assist in identifying issues that require system-based responses. However, they can also contribute to stereotyping of Indigenous Peoples as having, for example, poor health lifestyles (e.g., in the case of diabetes) or negligent mothers (e.g., in the case of FASD). Harm may be especially likely when research is repetitive and re-quantifies well-established issues. In his 2015 article in *The Guardian*, Scott Gorringe explored deficit discourses regarding Indigenous Peoples [22]. He described a deficit discourse as "a mode of thinking that frames and represents Aboriginal identity in a narrative of negativity, deficiency and disempowerment" [22]. As healthcare providers digest and apply academic literature to practice, health research can have a negative impact on healthcare. If health research supports stereotypes about Indigenous Peoples, and over-emphasizes stigmatized health challenges, this may affect the cultural safety of Indigenous people seeking care. By contrast, reframing research around strengths can focus on enabling individuals and communities through familiar cultural and traditional approaches to health and healthcare. As an alternative, strength-based health research is research that focuses on positive aspects of health, or positive approaches or solutions to negative health issues, i.e., ways of knowing, knowledge and skills that can lead to health transformations or health gains.

Objectives

The purpose of this paper is to delineate the potential consequences of deficit-based Indigenous health research, how to avoid these harms, and how to consider strength-based research as an alternative. Relevant ethical guidelines – as they relate to the concept of deficit-based research – are reviewed. Aspects of deficit-based research that do not align with these ethical guidelines are identified and discussed, and we then explore measures to avoid harm that are drawn from ethical principles, literature, and research examples. We draw upon ethical guidelines and principles to examine how, despite the notion that health research is often deficit-based, this approach is not typically useful on an Indigenous community level. Additionally, we discuss how alternative strength-based approaches and/or reframing of health inequities are/is needed to avoid the continued marginalization of Indigenous Peoples.

Definitions

In this paper, *Indigenous* in the context of Canada will refer to the First Nations, Métis and Inuit peoples; Indigenous may also refer to peoples globally who occupy their traditional and historic territory. Indigenous *community* will not necessarily refer to a geographically defined community, but instead any group of people that defines themselves as an Indigenous community.

Stereotyping refers to an over-generalized belief about a given group of people. Stereotypes involve the assumption that a general characteristic applies to every person in this category of people. *Stigmatization* refers to explicit or implicit labeling of something as disgraceful. A stigmatized topic is associated with general public disapproval.

Avoidance of Stigmatization and Stereotyping

Deficit-based research can contribute to stigmatization when problematic health issues are repeatedly characterized in the context of a specific population. Additionally, when any given health deficit is repetitively associated with Indigenous Peoples through research, there is risk of stereotyping. Unfortunately, due to a lack of critical exposure in education and media, deficit-based research given without proper framing can perpetuate negative characterizations of Indigenous Peoples [23]. If Indigenous health issues are presented in academic literature with little historical and social contextual information, an "epidemiological paradox" arises. Although it is in society's interest to bring attention to health risks, this same attention can repeatedly portray Indigenous Peoples negatively and lead to a presumed "population level pathology" that is "an insidious, pervasive and subtle form of structural racism and discrimination" [24]. OCAP principles point out that some information resulting from research can "lead to discrimination and stigmatization" of communities [14]. Nevertheless, deficit-based research can be beneficial in identifying and offering treatment for health problems. To avoid transferring the stigma of a stigmatized health issue to entire communities or peoples, researchers can engage in a discussion of the influence of colonization and Westernization, thereby reframing the issue and reassigning the shame to such influences rather than to Indigenous Peoples.

One example of a health challenge with associated stigma is type 2 diabetes. Research into high levels of type 2 diabetes in Indigenous communities has included substantial investigation of potential genetic explanations, sometimes referred to as the "Thrifty Gene Hypothesis" [25]. This hypothesis postulates that some Indigenous Peoples are genetically predisposed to diabetes. However, both early and more contemporary researchers investigating this topic ultimately conceded that genetics does not capture the complexity of factors resulting in high levels of type 2 diabetes in some Indigenous populations, and argued for the greater attention to the effects of various colonial policies. But this extensive body of work on the genetic causes of type 2 diabetes continues to be cited today [25]. Hence, there is potential for deficit-based narratives regarding stigmatized health issues to become deeply rooted stereotypes if precaution is not exercised.

To avoid stigmatization in deficit-based research, health issues must be contextualized. Such an example is demonstrated in a 2016 study evaluating a harvest sharing program in Northern Ontario [26]. The authors highlighted a number of potentially stigmatizing deficits including reduction in dietary quality, physical activity and an increase in obesity in First Nations communities [26]. However, the authors explained that the reasons for these challenges were complex and include the transition to Western lifestyles that First Nations experience, which at least in part contributes to their health challenges [26]. In this way, the authors were laudably careful to contextualize their findings and to inform readers of some of the root causes of the examined deficits, thus mitigating risk of stigma.

Importantly, avoidance of harm does not equate to total avoidance of research concerning stigmatized topics. For example, if a community would like to explore local prevalence of type 2 diabetes, such as in a 2009 study by Wahi and colleagues, the research can confer benefit in that they provide a community with desired information [27].

When Stereotypes Interfere with Care

A major problem with the stereotypes supported by deficit-based research is that they pose a risk to Indigenous people when seeking care, especially if stereotypes are related to stigmatized health topics such as addiction. In their 2015 report, Allan and Smylie discussed barriers to care that Indigenous Peoples face, including racism [23,28-30]. Stereotypes such as the 'drunken Indian' affect how health providers interact with Indigenous patients. The deaths of Brian Sinclair in a Winnipeg emergency room and Hugh Papik in his elder's home are stark examples of this. Both Indigenous men were presumed to be drunk although they were not, and died of a bladder infection and a stroke, respectively, while trying to access care [23,31,32].

Researchers should consider the extent to which their research may reinforce stereotypes about Indigenous Peoples. If a given health issue has been extensively characterized, it may be worthwhile reframing the approach or researching topics identified as being of interest to communities, rather than potentially contributing to further stereotype reinforcement.

Responsiveness to Community Needs

A significant issue that can arise in deficit-based research is a lack of responsiveness. Responsiveness is a principle that refers to the obligation of global health researchers to use research to respond to inequities affecting the participants in their research, rather than exploit inequities for research or conduct research irrelevant to the communities involved [20]. This concept of responsiveness is outlined in the CCGHR Principles, and aligns with the Inuit Tapiriit Kanatami's assertion that research must be a tool for creating social equity [19]. Deficit-based research may be particularly prone to identifying inequities without explaining how such an identification acts to mitigate inequities or confer benefit. It is important to note that Indigenous Peoples may be polarized on certain topics, including whether or not exploration of a particular health deficit confers sufficient

benefit or produces significant harm. In these scenarios, researchers are encouraged to engage all stakeholders to the extent possible, but to also consider the risk of increasing polarization, which may "actually impede the advancement of social justice" [3]. The CIHR guidelines recommend collaborating with community members in cases of polarization to assess conflicts of interest, and to look to existing community structures and systems for resolving disputes [12].

Historically, lack of responsiveness has been an issue in Indigenous health research, and is exemplified by the nutritional experiments carried out on children who were forced into the residential school system. These experiments were carried out despite the government and researchers already recognizing malnutrition as a systemic issue in residential schools [2]. Rather than trying to intervene to improve the nutritional status of these children, the researchers exploited the malnourished children to test various hypotheses [2]. The research characterized by Mosby demonstrates that researchers working in the residential school system were not responsive in this sense but instead exploited and perpetuated an existing inequity (starvation and malnutrition) with no benefit to those being studied.

Problems relating to responsiveness are also a contemporary issue. For example, a 2011 study of the prevalence of tobacco, alcohol and drug use by Indigenous youth in Canada was characterized using existing data [33]. This information may have been useful in attracting resources or informing policy. However, such benefits were not discussed, contextualization for the issue was not provided, and no disclosure of Indigenous collaboration was present. Overall, it is impossible for a reader to discern if such research was desired by or responsive to the interests of Indigenous Peoples. Deficit-based research is particularly prone to lacking responsiveness because identifying a problem, even when researchers are well-intentioned, does not intrinsically result in transformative health interventions or improved social equity. Importantly, responsiveness can be a component of any research methodology. For example, responsiveness does not exclude randomized controlled trials where benefit cannot be known in advance, if the involved communities agree that the trial has the potential to result in benefit.

Authentic Partnering and Indigenous Voice to Combat Deficit Narratives

Deficit-based research may be particularly prone to harming Indigenous communities if researchers do not engage Indigenous stakeholders. An important point to consider with regard to Indigenous health research, and especially for deficit narratives, is the difficulty for non-Indigenous researchers to provide the full context regarding any particular deficit. A non-Indigenous researcher can never be an expert on the lived experience of health challenges facing Indigenous Peoples [34]. Additionally, potential benefit of characterizing a health deficit cannot be presumed without Indigenous engagement.

Not recognizing Indigenous voices creates epistemic injustice by excluding members of Indigenous populations from formulating their own research and asserting their self-determined knowledge. In their discussion of epistemic injustice in healthcare, Carel and Kidd assert that healthcare providers are epistemically privileged because they "occupy an authoritative procedural role in epistemic exchanges, for instance by acting as gatekeepers controlling which persons and groups are included, and what degree of credibility and authority they are assigned" [35]. The same epistemic privilege applies to Western researchers. The frameworks already referenced support Indigenous engagement in all aspects of research: The First Nations Principles of OCAP®, the CCGHR principle of shared benefits and inclusion which draws upon OCAP®, the Inuit Tapiriit Kanatami's National Inuit Strategy on Research, and community-specific policies [5,6,14,19,20]. The substantial resources required for meaningful engagement may have historically discouraged some researchers, as funding systems have tended to be inadequate for such approaches. Recently, the Network Environments for Indigenous Health Research (NEIHR) Program has been established by CIHR [36]. This initiative is important and timely and speaks to the fundamental idea that Indigenous peoples and communities are taking control of their own research and community needs [36].

Another example of deficit-based research that does not disclose any sort of Indigenous participation is a 2011 study relating to effects on Inuit children of maternal 'binge drinking' during pregnancy [37]. With a lack of discussion around the factors related to consumption of alcohol by pregnant Inuit women, the article left readers to draw their own conclusions, potentially based on stereotypes and bias. Inuit participation could have resulted in helpful contextualization. By contrast, an example of research that effectively demonstrated authentic partnering and privileging of Indigenous voice is a 2014 study relating to enacted Stigma and HIV Risk behaviours among sexual minority Indigenous youth in Canada, New Zealand, and the United States [38]. This paper included multiple Indigenous authors, Indigenous and sexual minority research team members, Indigenous advisory groups, and community consultations [38]. Before the study, the research team additionally consulted with other Indigenous Peoples in Canada, New Zealand, and Native American researchers about the "purpose, design, sampling, and measurement issues" [38]. A Māori advisory group was consulted continuously about interpretation and dissemination, and additional advisory engagement with other Indigenous entities was sought [38]. This work clearly prioritizes Indigenous voice and took a number of steps to engage guidance from Indigenous stakeholders.

When weighing the benefits and harms of research, one must consider restoring control to Indigenous Peoples as a benefit. Additionally, perpetuation of a deficit-discourse should be considered a valid harm. An important way to restore control is to privilege Indigenous voices in Indigenous health narratives, which will in turn reduce risk of harm from deficit-based research due to Indigenous input on framing and dissemination. There may, nonetheless, be situations where disagreement about interpretation arise between researchers and the community [3]. At minimum, if these cannot be resolved, the TCPS2 states that researchers should either provide opportunity for the community to communicate its views, or accurately and fairly report the disagreement in any dissemination activities [3]. However, researchers must be cautious to consider what harms may be

associated with disseminating information that a community believes to be inaccurate, especially in relation to deficit-based topics. Some ethical principles, such as the OCAP principle of control, suggest that Indigenous communities should always direct how knowledge is shared [15].

Methodological Choices

While implementing Indigenous voice in deficit-based discourse requires a conscious effort, some methodologies and approaches are helpful in naturally including Indigenous voice. Community-Based Participatory Research (CBPR) is an approach to research that inherently facilitates inclusion of Indigenous voices. The intention of CBPR is to increase community ownership of research [39]. CBPR strives for relevancy to local community, enhances local capacity, builds trust, imparts knowledge of community contexts, and creates results directly used for sustainable change [39]. Community members become researchers and come to understand their own circumstances on their terms [39]. CBPR thus satisfies the requirements of numerous ethical guidelines, including TCPS2's requirement of community engagement, the OCAP principle of control, Inuit Tapiriit Kanatami's National Inuit Strategy on Research's goal of self-determination, and the CCGHR principle of authentic partnering [3,15,20,21].

An example of CBPR is demonstrated in a 2015 study examining children's experiences of food insecurity in Alexander First Nation [40]. In this project, high school co-researchers conducted photovoice interviews, were included in data analysis and in the development and dissemination of a photobook [40]. The project had a community research committee, which included community members, and the community is listed as an author on the resulting publication [40]; the committee approved the research protocol and the published manuscript. The photobook resulting from the project served as a community knowledge dissemination tool for community members; and the incorporation of co-researcher perspectives provided important information for the research committee, who were in a position to elicit change within their community [40]. This research engaged the community in various ways and facilitated local leadership in the research. When researching a sensitive and potentially stigmatized topic such as food insecurity, CBPR may be a particularly helpful approach to avoid harm and confer benefit.

Acknowledgement of Community Strengths

Questioning and deconstructing deficit-based approaches to research does not mean denying the existence of health inequities faced by Indigenous communities. However, in 2019, it is also fair to say the majority of health deficits in Indigenous communities in Canada have been extensively quantified. Many health researchers have been advocating a switch from deficit-based narratives to a strength-based narrative. As described above, strength-based research can amplify existing capacities in Indigenous communities to address health issues, rather than focusing on community 'shortcomings' or 'deficits' [41-43]. This can provide a good model through which to identify health challenges, but also to address and present them in a positive and solution-oriented way. Indigenous communities have strengths that contribute to their well-being, for example "norms of sharing and reciprocity and traditional perspectives, respect for the wisdom of elders, balance, and interconnectedness with nature" [44].

One example of strength-based research is Gabel and colleagues' 2016 project "Using Photovoice to Understand intergenerational Influences on Health and Well-Being in a Southern Labrador Inuit Community" [45]. This project explored intergenerational relationships using a CBPR approach and the arts-based method of photovoice [45]. The authors concluded that within the community there were strong relationships between old and young generations, and that this contributed significantly to the health and wellbeing of the community [45]. They point to these relationships as a significant strength and asset in promoting health and well-being in Indigenous communities [45]. Photovoice is a powerful participatory technique that enables participants to 1) assess community strengths and concerns, 2) communicate community ideas to researchers and policymakers, 3) put the power of photography into the hands of community members, 4) promote critical dialogue and knowledge about issues through group discussion of photos, 5) facilitate power-sharing by having the participant rather than the researcher determine the subject and meaning of the photo, 6) facilitate a richer understanding of the issues being studied, and 7) help participants reflect on and recognize their own perspectives on issues facing their communities [45-50]. It is an ideal approach for research with Indigenous communities because it "fosters trust, gives community members ownership over research data, and shifts the balance of power to community members"; and it is consistent with a CBPR paradigm [49,51-53].

This research described a substantial community strength that already exists. They point to intergenerational relationships as a way to support cultural continuity and to promote overall wellbeing of community members [45]. In their paper, the authors also highlighted how cultural continuity was disrupted by colonization, and that communities with continuity were overall healthier [45]. This is an excellent example of research that frames Indigenous issues in the context of colonization, works closely with the community participating in the research, and points out features that will be useful to promoting community well-being and perhaps is also useful to promoting well-being in other Indigenous communities. Rather than presenting information that can lead to shame and stereotyping, their research can be empowering for Indigenous communities. One can see then how this research may be: 1) more useful to Indigenous communities than the deficit-based research described earlier and 2) does not stigmatize or shame the community or Indigenous Peoples as a group.

Conclusions

Deficit-based research risks contributing to the stereotyping and stigmatization of Indigenous Peoples. Strength-based and solution-oriented research provides a promising alternative to this normative approach. Ensuring that Indigenous Peoples have authority over how they are researched and how they are portrayed as a result of that research is critical to producing effective and beneficial research [15]. Understanding the problematic history of Indigenous health research in Canada demands significant accountability on the part of researchers to communities. Considering how deficit-based research may stigmatize communities is a harm that must be addressed in any project. Likewise, researchers should consider how their work is contributing to a more equitable future for participants, and how the work itself is responsive to existing inequities. Framing Indigenous health disparities in an Indigenous context must expressly encompass colonization and Westernization, so that research can contribute to how non-Indigenous Peoples view Indigenous Peoples. Finally, strength-based and/or solution-oriented research provides ways for researchers to enact the significant elements in existing ethics and good practices guidance. A simple and important measure to produce good Indigenous health research is to privilege Indigenous voice, as Indigenous Peoples are primary stakeholders in the research with their communities. Indigenous health research is inextricably connected to how the wider society perceives Indigenous Peoples, and how Indigenous Peoples are perceived inherently affects their overall health and well-being – and this must guide the approach of ethicists and health researchers to this field of work.

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