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DEPARTMENTS		DÉPARTEMENTS
Jim Henderson and Jessie Loyer	1	Message from the Guest Editors / Message des rédacteurs invités
RESEARCH ARTICLE		ARTICLE DE RECHERCHE
Sandy Campbell, Marlene Dorgan, and Lisa Tjosvold	5	Creating Provincial and Territorial Search Filters to Retrieve Studies Related to Canadian Indigenous Peoples from Ovid MEDLINE
FEATURES		MANCHETTES
Kevin Read, Gail Mc Donald, Brad Mackay, and Eugene Barsky	11	A Commitment to First Nations Data Governance: A Primer for Health Librarians
Janet Smylie, Michelle Olding, and Carolyn Ziegler	16	Sharing What we Know About Living a Good Life: Indigenous Approaches to Knowledge Translation
Jessie Loyer and Marija Small Legs	24	Non-insured Health Benefits for First Nations and Inuit People: an Overview for Information Providers
Kathleen Murray	27	The Arctic Council: a Brief History, its Partnership with Indigenous Groups of the Arctic, and its Role in Uncovering and Addressing Health Issues in the Far North
Sigrid Brudie and Christy Garrett	32	Sources of Alaska Native Health Data and Statistics
BOOK REVIEWS		CRITIQUES DE LIVRES
Lisa Demczuk	35	Birth on the Land: Memories of Inuit Elders and Traditional Midwives
Minakshi Sharma	37	Knowledge Translation in Context: Indigenous, Policy and Community Settings
Jennifer Owens	39	An Invited Threat, Just a Story, and Kiss Me Deadly.
PRODUCT REVIEW		ANALYSE DE PRODUITS
Karen Hine	41	Evernote

	COLUMNS	CHRONIQUES
Christie Hurrell	44	Current Research
	NEWS AND NOTES	NOUVELLES ET NOTES
Jim Henderson and Jessie Loyer	46	Online Sources of Aboriginal Health Information
	ANNOUNCEMENT	COMMUNIQUÉ
Natalie Clairoux and Lindsey Sikora	47	Scaling New Heights Together in 2014 at CHLA–ABSC in Montreal!

DEPARTMENTS / DÉPARTEMENTS

Message from the Guest Editors

Welcome to JCHLA/JABSC's first special issue! It brings together a wide range of experiences and issues around Aboriginal health information and, as guest editors, we too are representative of the varied roles of librarians working in these areas. Jessie Loyer, Cree-Métis, is a member of the Michel First Nation and a librarian at Mount Royal University. Jim Henderson has worked in British Columbia and Quebec developing information services for professionals and researchers working with Aboriginal people.

This issue responds to growth in Aboriginal health as a field of study. First Nations, Inuit, and Métis peoples, collectively the Aboriginal or Indigenous peoples of Canada, make up the fastest growing and youngest segment of the Canadian population. The disparities in health and living conditions between Aboriginal and non-Aboriginal Canadians are significant and demonstrate the effects of inequities in the social determinants of health [1]. More Aboriginal people live in poverty and, hence, in poor health. Inequities in access to health care and education and in living conditions result in higher child mortality, shorter life expectancy, and greater incidences of chronic conditions and infectious diseases. Historical issues—for example, residential schools and racism—exacerbate these challenges. Aboriginal cultures are resurgent, demonstrating resilience after years of suppression and historical challenges and health—especially culturally relevant and self-determined health—is an important element of this resurgence.

Growth in the field of study generates increased demand for Aboriginal health information and presents unique challenges for libraries with its dispersed, multidisciplinary literature. Campbell, Dorgan, and Tjosvold report on progress developing extensive MEDLINE search hedges for Canadian Aboriginal health information. Valuable insights into the challenges libraries face are provided through articles on knowledge translation and information literacy. Janet Smylie and colleagues review the considerations and cultural factors that lead to successful information programs in Aboriginal communities. Loyer and Small Legs provide an interesting perspective on non-insured health benefits and health literacy. We are pleased that this issue presents an international perspective. The article by Kathy Murray on the Arctic Council makes it clear that international borders are less relevant to Indigenous peoples and highlights the importance and variety of sources, including those for grey literature, to be included in searches on Aboriginal health. Brudie and Garrett report on efforts in Alaska to organize data on Aboriginal populations, ensuring compatibility with other US programs.

Message des rédacteurs invités

Bienvenue au premier numéro spécial du JABSC / JCHLA! Il rassemble un large éventail d'expériences et de sujets traitant de l'information sur la santé des autochtones et, à titre de rédacteurs invités, nous représentons nous aussi la variété des rôles qu'assument les bibliothécaires en ces domaines. Jessie Loyer, Crie-métis, est membre de la « Michel First Nation » et est bibliothécaire à l'Université Mount Royal. Jim Henderson a œuvré en Colombie-Britannique et au Québec au développement de services d'information à l'intention des professionnels et des chercheurs travaillant auprès des populations autochtones.

Le présent numéro résulte d'une réflexion face à l'importance que revêt la santé des autochtones comme domaine d'étude. Les Premières nations, les peuples Inuit et Métis, appelés collectivement Premières nations ou peuples autochtones du Canada, constituent le segment de la population canadienne le plus jeune et celui dont la croissance démographique est la plus rapide. Les disparités en santé et en conditions de vie entre les Canadiens autochtones et non autochtones sont importantes et sont manifestes des effets des iniquités des déterminants sociaux et de la santé [1]. Davantage de peuples autochtones vivent dans la pauvreté et partant, ont un piètre niveau de santé. Les iniquités d'accès aux soins médicaux et à l'éducation, ainsi que celles liées aux conditions de vie résultent en un taux de mortalité plus élevé, en une espérance de vie plus courte, et en une incidence plus élevée d'états de santé chroniques et de maladies infectieuses. Des préoccupations historiques—par exemple, les pensionnats et le racisme—exacerbent ces défis. Les cultures autochtones sont en résurgence, elles font preuve de résilience après des années de répression et de déni; et la santé—particulièrement ces éléments de santé liés à la culture et à l'autodétermination—constitue un important élément de cette résurgence.

La croissance dans le domaine des études génère une demande croissante d'information en santé des autochtones et représente des défis uniques pour les bibliothèques en ce qui concerne la diversité et la multidisciplinarité de la documentation. Campbell, Dorgan et Tjosvold nous informent des progrès dans la mise en valeur intensive d'éléments de recherche en information en santé des autochtones du Canada dans MEDLINE. D'intéressantes perspectives relatives aux défis auxquels font face les bibliothèques sont l'objet d'articles traitant du transfert des connaissances et de la littératie en information. Janet Smylie et ses collègues passent en revue les considérations et les facteurs culturels garants de réussite des programmes d'information au sein des communautés autochtones. Loyer et Small Legs offrent une perspective intéressante sur les soins médicaux non assurés et sur la littératie en santé. Nous nous réjouissons du fait que ce numéro offre une perspective internationale. L'article de Kathy Murray

A number of Aboriginal communities are taking over governance of their health care, leading to progress on the social determinants of health as well as the health of their members. The article by Read et al. reports on self-governance in the field of data and elucidates the principles of ownership, control, access, and possession (OCAP) to address the need to respect community interests in using data, perhaps suggesting the political aspect that comes into play often in Aboriginal health. We are pleased that the issue contains two articles on data management, as discussion in the context of Aboriginal health information presents a useful perspective for health libraries on this burgeoning field. This issue highlights the usefulness of a cross-cultural lens and presents the range of challenges and means of addressing them for libraries working with Aboriginal researchers and communities.

As well as the relevance of the social determinants of health, many Aboriginal cultures embrace a holistic, integrated view of health, land, and environment. We hope that readers gain understanding of these shifts in perspective needed to work in Aboriginal health information through the lens of authors that include librarians and those of Aboriginal descent. Although the use of standard sources, such as MEDLINE which indexes scholarly publications, is essential, grey literature sources need to be consulted. Sources covering the broader range of disciplines used by librarians working in public health are therefore relevant, with a nuance of integration that is unique to Aboriginal health information.

We would suggest that library values enable work with Aboriginal health information and partnerships with Aboriginal peoples. Reciprocity with aboriginal communities would not be uncomfortable for librarians; we have a lot to offer each other. Historical and demographic challenges of aboriginal communities parallel the challenges libraries are currently facing with threats to services from budget cuts and rapid changes in information technology. The National Network of Libraries of Medicine Pacific Northwest Region's Tribal Connections project launched in 1997 helped 16 American Indian and Alaska Native groups with Internet connectivity and access to web-based health resources [2, 3]. The community-based, culturally sensitive approach to outreach led to partnerships successful in building community capacity if not always technical infrastructure and use of web resources. Respect for libraries as keepers of community knowledge and our non-judgmental, respectful approach was recognized. The values and approach of the librarians in the project engendered trust from the diverse communities participating. Through the process, past issues with government and university researchers made aboriginal communities distrustful, yet the librarians were able to build relationships "built on mutual, time-tested trust and respect" [2]. Organizational approaches of libraries and librarians' professional values enable us to work with culturally diverse communities and enable knowledge translation with strategies described in this issue.

Despite the breadth of knowledge evident in this issue, many gaps remain. The organization and availability of literature on First Nations, Metis, and Inuit health is concerning, especially with the closure of the National

sur le Conseil de l'Arctique énonce clairement le fait que les frontières internationales ont moins d'importance pour les peuples autochtones et met en évidence l'importance de l'inclusion de sources diversifiées, y compris celles de la documentation parallèle dans les recherches sur la santé des autochtones. Brudie et Garrett nous informent des efforts déployés en Alaska pour organiser les données sur les populations autochtones de façon à ce qu'elles soient compatibles à celles d'autres programmes des États-Unis.

Plusieurs communautés autochtones prennent en charge la gouvernance de leurs soins de santé; il en résulte des progrès au niveau des déterminants sociaux de la santé de même qu'à celui de la santé des membres de leurs communautés. L'article de Read et al. traite d'autorégulation dans le domaine des données et précise les principes de propriété, de contrôle, d'accès et de prise de possession face à la nécessité du respect des intérêts des communautés quant à l'utilisation des données, suggérant la possibilité que l'aspect politique intervient souvent en santé des autochtones. Nous nous réjouissons du fait que ce numéro comporte deux articles qui traitent de la gestion des données, puisqu'une discussion dans le contexte de l'information en santé des autochtones offre une perspective utile pour les bibliothèques de la santé, particulièrement en ce domaine en plein essor. Ce numéro met en évidence l'utilité de visions interculturelles et présente l'éventail des défis et des moyens d'y faire face pour les bibliothèques qui collaborent avec des chercheurs et des communautés autochtones.

En plus de la pertinence des déterminants sociaux de la santé, plusieurs cultures autochtones préconisent une vision holistique intégrée, regroupant santé, territoire et environnement. Nous espérons que les lecteurs acquerront une meilleure compréhension de ces perspectives différentes, nécessaires au travail d'information en santé des autochtones, grâce à la vision qu'en ont les auteurs, lesquels comprennent des bibliothécaires et des personnes d'origine autochtone. Alors que l'utilisation de sources conventionnelles telles que MEDLINE s'avère essentielle, cette dernière indexant les publications érudites, la documentation parallèle doit elle aussi être consultée. Des sources tenant compte d'un registre plus large de disciplines, utilisées par des bibliothécaires qui travaillent en santé publique sont dès lors plus pertinentes, pondérées d'une intégration nuancée particulière à l'information en santé des autochtones.

Nous suggérons que les valeurs de la bibliothèque rendent possibles le travail d'information en santé des autochtones et les partenariats avec les peuples autochtones. La réciprocité avec les communautés autochtones ne saurait être désagréable pour les bibliothécaires; nous avons beaucoup à nous offrir les uns aux autres. Les défis historiques et démographiques des communautés autochtones trouvent l'équivalent de ceux auxquels font face actuellement les bibliothèques quant aux menaces de services découlant de compressions budgétaires et des changements rapides en technologie de l'information. Le projet « National Network of Libraries of Medicine Pacific Northwest Region's Tribal Connections » lancé en 1997 a aidé 16 groupes d'Indiens d'Amérique et d'autochtones d'Alaska à obtenir le branchement Internet et l'accès à des ressources Internet en santé [2, 3]. L'approche d'extension des services misant sur la communauté et respectueuse de la culture a mené à des partenariats réussis qui ont permis de renforcer les capacités

Aboriginal Health Organization (NAHO), which produced and made available online many reports on Aboriginal health topics (its web site will continue to host these reports until 2017). Although international perspectives are presented here, gaps in the bibliographic control of literature do not reflect the wide-ranging international and interdisciplinary nature of Aboriginal health research. Analyses of the databases from various disciplines important in Aboriginal health need to be more in-depth, and terminology remains a challenge, with Canadian usage standardized as First Nations, Inuit, and Métis, whereas American Indian and Alaska Native are used in the US, with MeSH using "Inuits" even though "Inuit" is plural.

Working on this Special Issue has been a pleasure and an honour. We thank the JCHLA editorial team for this opportunity and their professional approach. We trust that this issue will be valuable to readers, introducing and advancing the field of Aboriginal health information.

Ekosi pitama (that is all, for now).

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References

1. Marmot M, et al. For the Commission on Social Determinants of Health. Closing the gap in a generation: health equity through action on the social determinants of health. *Lancet*. 2008;372:1661–1669. doi: 10.1016/S0140-6736(08)61690-6.
2. Press NO, et al. Program management and policy issues in information outreach: lessons from Tribal Connections. *J Health Soc Policy*. 2003;17(3):1–20. PubMed PMID: 17824583. doi: 10.1300/J045v17n03_01.
3. Wood FB, Sahali R, Press N, Burroughs C, Mala TA, Siegel ER, Rambo N, Fuller SS. Tribal connections health information outreach: results, evaluation, and challenges. *J Med Libr Assoc*. 2003;91(1):57–66. PubMed PMID: 12568158; PubMed Central PMCID: PMC141188.

de la communauté voire, la mise en place d'infrastructures techniques et autres, ainsi que l'utilisation de ressources Internet. Le respect accordé aux bibliothèques comme gardiennes du savoir communautaire, ajouté à notre approche respectueuse exempte de préjugés ont été bien reconnus. Les valeurs et l'approche des bibliothécaires du projet ont suscité la confiance des diverses communautés participantes. Au cours du projet, en dépit de divergences passées avec le gouvernement et des chercheurs universitaires qui avaient miné la confiance des communautés, les bibliothécaires ont réussi à établir des relations «s'appuyant sur la confiance et le respect mutuels éprouvés dans le temps» [2]. Les valeurs professionnelles des approches organisationnelles des bibliothèques et des bibliothécaires nous ont permis de travailler avec des communautés de cultures différentes et d'assurer le transfert des connaissances grâce aux stratégies décrites dans le présent numéro.

En dépit de l'ampleur des connaissances mise en évidence dans le présent numéro, plusieurs lacunes demeurent. L'organisation et la disponibilité de la documentation traitant de la santé des Premières nations, des Métis, et des Inuit, demeurent une préoccupation, particulièrement en raison de la fermeture de l'Organisation nationale de la santé autochtone (ONSA), laquelle a produit et rendu accessibles en ligne plusieurs rapports traitant de sujets liés à la santé des autochtones (son site Internet maintiendra l'accès à ces rapports jusqu'en 2017.) Bien que les perspectives internationales soient présentées ici, des lacunes de contrôle bibliographique de la documentation ne reflètent pas la nature interdisciplinaire et internationale étendue de la recherche en santé des autochtones. Des analyses plus poussées des bases de données de disciplines diverses, importantes en santé des autochtones, s'imposent; et la terminologie demeure un défi, alors que l'usage canadien a normalisé les expressions «Premières nations», «Inuit» et «Métis», les États-Unis utilisent encore «American Indian» et «Alaska Native»; et les descripteurs médicaux (MeSH) utilisent le terme «Inuits» alors même que le mot «Inuit» est pluriel.

Travailler à la réalisation de ce Numéro spécial a été un plaisir et un honneur. Nous tenons à remercier l'équipe de rédaction du JABSC de cette possibilité et de l'approche professionnelle dont elle a fait preuve. Nous espérons que le présent numéro sera apprécié par les lecteurs, et qu'il sera promoteur de l'information en santé des autochtones.

Ekosi pitama (c'est tout pour l'instant!)

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RESEARCH ARTICLE / ARTICLE DE RECHERCHE

Creating Provincial and Territorial Search Filters to Retrieve Studies Related to Canadian Indigenous Peoples from Ovid MEDLINE¹

Sandy Campbell, Marlene Dorgan, and Lisa Tjosvold

Abstract: **Introduction:** Performing systematic review searches related to Canadian Indigenous peoples (First Nations, Inuit, and Métis), particularly in areas of public health, is difficult because Medical Subject Headings (MeSH) terms for both Indigenous peoples and geography do not retrieve all relevant articles in Ovid MEDLINE. Text-word searching for Canadian Indigenous peoples presents challenges in the varieties of names, spellings, and languages. A series of Canadian Indigenous peoples filters were designed to retrieve larger numbers of relevant articles. **Objectives:** The objectives of this work were (i) to create first-generation search filters that retrieve studies from the Ovid MEDLINE database related to Canadian Indigenous peoples, (ii) to determine whether or not the filters retrieve more records than do searches using the MeSH headings alone, and (iii) to determine how many of the additional records are relevant. **Methods:** Key terms describing both Canadian Indigenous peoples and Canadian geography were identified using government, historical, and ethnographic publications. Name lists included current and historical names in multiple languages, as well as local and settlement names, and names of linguistic groups. Filters, employing both text-word and MeSH terms were created for each province and territory, excluding Prince Edward Island. Search results were reviewed for false recalls related to terms with multiple meanings and groups of people whose lands straddle provincial and territorial borders. Revised searches were refined with additional terminology that implies the presence of Indigenous peoples. Duplicate records were removed from both the MeSH searches and the filter searches. Results from the MeSH searches were then removed from the results of the filter searches. The remaining results were analyzed for relevance. **Results:** Twelve Ovid MEDLINE filters were created and the challenges involved in creating them were documented. The filters increased recall by 58 articles, 464% over MeSH searches alone. Of the additional articles retrieved, 28 (100%) met the criteria for relevance. **Discussion:** The lists of challenges identified in the filter creation will assist other searchers in developing similar filters. The filters allow searchers to retrieve substantially more articles than is currently possible with the MeSH terms alone.

Introduction

Performing systematic review searches related to Canadian Indigenous peoples, particularly in areas of public health, is difficult because MeSH terms for both Indigenous peoples and geography do not retrieve all relevant articles in MEDLINE. Text-word searching for Canadian Indigenous peoples presents challenges in the varieties of names, spellings, and languages. A series of Canadian Indigenous peoples filters were designed to retrieve larger numbers of relevant articles.

Objectives

The objectives of this work were (i) to create first-generation search filters that retrieve studies from the Ovid

MEDLINE database related to Canadian Indigenous peoples, (ii) to determine whether or not the filters retrieve more records than do searches using the MeSH headings alone, and (iii) to determine how many of the additional records are relevant.

Background

Searching comprehensively in the health literature for studies related to Indigenous peoples in Canada presents many challenges. Additionally, because health care administration and delivery fall under provincial jurisdiction in Canada, researchers frequently undertake studies related to the health of Indigenous peoples within a specific province or territory. To streamline and simplify these searches, the research team undertook to create hedges or

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filters to retrieve studies related to Indigenous peoples in all of Canada's territories and provinces. The first suite of filters has been designed for the Ovid MEDLINE database, and can be accessed online at the University of Alberta's [Education and Research Archive \(ERA\)](#).

Search filters or hedges "are pre-tested strategies that identify the higher quality evidence from the vast amounts of literature indexed in the major medical databases" [1]. First-generation filters are "subjectively derived, based on librarian searcher expertise, relying on knowledge of the database structure, content and thesaurus, along with the clinicians' subject knowledge. Measures of how effective the search filter performs on an independent set of relevant records are not calculated" [2]. Klatt observed that "the use of a subject hedge can greatly improve the quality and accuracy of a mediated search on MEDLINE or any other database" [3]. Although methodological filters are readily available [4], less work has been done in creating geographically based filters or filters that identify publications related to Indigenous peoples. Geographic filters have been developed, for example, for Africa [5] and the European Union [6]. Murray [7] created a filter to retrieve all materials related to the Circumpolar North, but no geographic filters for the Canadian provinces and territories have been created. Similarly, some work on filters to identify studies related to Indigenous peoples has been done. For example, Sladek et. al. recently tested a filter to identify Australian Aboriginal and Torres Strait Islander health literature [8]. In the Canadian context, Guistini [9] has created a list of useful Indigenous-related terms that could be combined to create a filter. However, the purpose of this research project was to create "cut and paste" filters that anyone could copy into the Ovid MEDLINE search box and execute immediately.

Some of the challenges involved in using MeSH terms to identify studies related to Indigenous peoples in Ovid MEDLINE are described in the literature [10]. Among these, the most critical is that the two primary MeSH terms that include Canadian Indigenous peoples (Indians, North American, and Inuits) are missing from many relevant records. These deficiencies may be attributed to the following:

- (i) The records have no subject headings attached. This may be because the articles are too new to be indexed or because they were added to the database when the journal in which they were published started to be indexed, but no back-indexing was done.
- (ii) The records are indexed at too high a level in the MeSH tree (e.g., articles indexed to the broader heading Genetic Groups, which includes many groups in Canada, in addition to Indigenous peoples, instead of using the more specific heading).
- (iii) No indexing at all was applied to represent ethnic, cultural, or linguistic groups in a study.
- (iv) The Indigenous peoples aspect of the study was not considered to be a primary focus of the study and, therefore, was not reflected in the subject headings.
- (v) Incorrect subject headings were applied.

Articles related to Canadian Indigenous peoples are sometimes indexed using four additional MeSH terms: "Health Services, Indigenous"; "Medicine, Traditional"; "Shamanism"; and "Ethnopharmacology". Like the primary two headings, these may also be applied inconsistently and some are also applied to other groups including Indigenous peoples outside Canada.

Similarly, geographic indexing is often missing or is too high level (e.g., North America instead of Canada) to be useful to retrieve all of the articles related to a specific geographic area. Occasionally the indexing is incorrect (e.g., MEDLINE record 23157729 is about Australian subjects [11] but is indexed to Northwest Territories).

Methods

Process for creating the filters

A team of three practising health librarians created the filters. Searches were executed between 1 May 2013 and 20 December 2013 on the Ovid MEDLINE database (Ovid MEDLINE In-Process and Other Non-Indexed Citations, Ovid MEDLINE Daily, and Ovid MEDLINE 1946 to Present). For each filter, with the exception of Nunavut, the librarians used the following process with no limits applied.

- (i) Team members searched a variety of sources for both Indigenous and geographic terms relevant to the particular province or territory. These included atlases, maps, ethnographic works, provincial and federal government web sites, Indigenous organizations' web sites, and other web sites.
- (ii) Team members searched relevant MeSH terms, broad Indigenous group or linguistic names, and terms that implied Indigenous people that were all qualified, where appropriate, with provincial or territorial geographic headings or text-word terms.
- (iii) Team members searched names of Indigenous groups or terms specific to the province or territory.
- (iv) Team members searched Indigenous place names including settlement names and reserves specific to the province or territory.
- (v) Team members searched Indigenous place names that also occur outside of Canada and qualified them with Canadian geographic terminology.
- (vi) Filters were constructed employing Boolean operators, adjacency, truncation, and nested logic as appropriate to create a single line search that can be cut and pasted into the Ovid MEDLINE search box.
- (vii) Results were reviewed to identify terms that retrieve high levels of irrelevant materials. Those terms were adjusted in the search. Where appropriate, specific terms that introduced too much irrelevant material were removed from the search using the "NOT" operator.

Development of the Nunavut filter followed the same process, except that it is based solely on geographic terms.

Recent Statistics Canada statistics [12] show that the population of Nunavut is largely (86.3%) Indigenous, so health studies in Nunavut are likely to be about Indigenous peoples. Studies done prior to Nunavut’s creation in 1999 are captured using town and settlement names.

Testing the filters

The filters were tested to determine whether or not they retrieved more relevant references in Ovid MEDLINE than did relevant combinations of MeSH terms and geographic headings using the following process:

- (i) Initial searches were conducted using MeSH terms and geographic headings only. **Figure 1** shows an example search conducted on 5 February 2014.
- (ii) Searches were conducted using the filters.
- (iii) Duplicate records were removed using the “remove duplicates from xx” command, where “xx” is the line number in the search.
- (iv) The results of the MeSH searches were then removed from the results of the filtered searches.
- (v) Titles and abstracts of the remaining results were reviewed for relevance to Indigenous peoples, health subjects, and geographic focus. Full articles were not reviewed.

Relevance was defined as including all of (i) reference to an Indigenous group, (ii) a reference to a health-related topic, and (iii) a clear indication that the study included people in the province or territory under study. Health-related topics were broadly interpreted to include not only clinical, genetic, and epidemiological studies, but also health policy, health administration, and environmental health. Studies of environmental pollutants were included if there was an indication that the pollutant was entering human food and water sources. Review of the records for relevance was done either by

the authors or by a graduate-level assistant who was trained for this task.

Results

Filter development

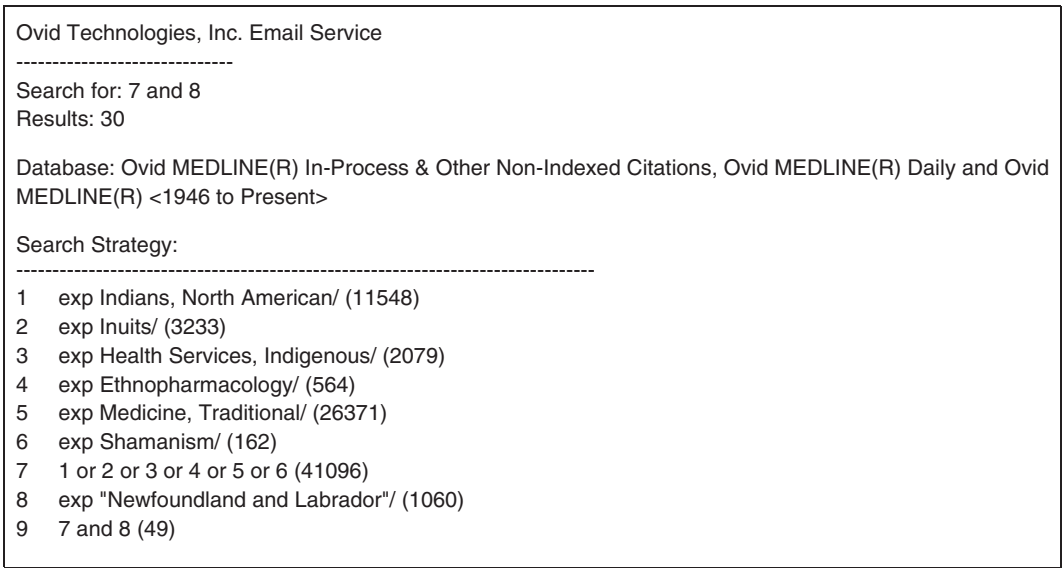
The result of the filter development phase of the project was 12 Ovid MEDLINE filters representing all Canadian provinces and territories, with the exception of Prince Edward Island where very few studies contain words that indicate the presence of Indigenous peoples. The versions of the filters used for the analysis in this paper are permanently archived in the University of Alberta’s institutional repository ERA. The filters were also published as independent documents on a University of Alberta Libraries LibGuide, “[Health Sciences Search Filters](#),” where they may be updated and revised where necessary. Each of the filters includes references to the sources used for the identification of relevant terms as well as notes for searchers.

In addition to the filters themselves, this project identified specific challenges involved in searching for both Indigenous peoples and geographic content in the Canadian context, and it confirmed the challenges identified by Mueller-Alexander and Seaton [13] and this team’s earlier exploratory work [14].

Challenges in text–word searching for Indigenous peoples

- (i) Although a study may refer to a specific group of Indigenous peoples who are resident within a particular province, authors may use general terms such as First Nations, Indigenous, Aboriginal, Métis, Amerindian, or Inuit, rather than specific group names to describe the study subjects making it

Fig. 1. Example of MeSH subject and geographic heading search.



impossible to use the group's name to identify specific groups.

- (ii) The terms "Native", "Aboriginal", "Indigenous" and "Indian" have historically been used to identify Canadian Indigenous peoples. However, the terms "native", "aboriginal," and "indigenous" also retrieve large numbers of references to plant and animal species. The term "Indian" retrieves studies related to people whose ethnic origin or country of birth is India.
- (iii) Within Canada, many groups overlap one or more provincial, territorial, or international border, which makes it more difficult to isolate studies about these people within a province or territory. (e.g., Cree, Gwich'in, Naskapi).
- (iv) The names of groups of Indigenous peoples may be recorded in various languages, (e.g., Inuit, Eskimo, Esquimaux).
- (v) The names of groups of Indigenous peoples have variant spellings or may be spelled incorrectly (e.g., Gwich'in, Kutchin, Gwitchin).
- (vi) The names of Indigenous groups may have changed over time (e.g., Dogrib–Tlicho).
- (vii) Terms for objects or concepts closely associated with Indigenous peoples (e.g., treaties, reserves, country-food) are sometimes the best indicators of Indigenous content in a study.
- (viii) Individual groups may be identified by their linguistic family (e.g., Algonquian), geographic subgroups (e.g., Woodland Cree), legal group names (Inuvialuit Settlement Area), and band or tribal names (e.g., Bigstone Cree).
- (ix) In some parts of Canada, the population is predominantly Indigenous, so the use of a unique place name (e.g., Sach's Harbour), can stand as a surrogate for terms relating to Indigenous peoples.
- (x) The names of some Indigenous groups are the same as Geographic terms (e.g., Bella Coola is

historically the name of a People and also of a town and a valley).

- (xi) Indigenous names have been used to name things or have been incorporated into trade names that are also present in the health literature (e.g., Iroquois homeobox genes).

Challenges in text–word searching for geographic terms related to Canadian Indigenous peoples

- (i) Place names have changed over time (e.g., the community of Hobbema, Alberta became Maskwacis, Alberta effective 1 January 2014. [15]).
- (ii) Place names may have spelling variants or common errors in spelling (e.g., Hudson's Bay and Hudson Bay).
- (iii) Place names are often replicated outside the province of interest (e.g., Deer Lake occurs in several provinces).
- (iv) Place names occur in the health literature in non-geographic contexts (e.g., Banff Test).
- (v) Some place names have other meanings that are significant in the health literature (e.g., Gamblers, Manitoba).
- (vi) Geographic boundaries change over time. (e.g., all locations in Nunavut were in the Northwest Territories before 1999).
- (vii) Authors may identify Indigenous peoples in large geographic areas (e.g., Mackenzie Valley Basin, Ellesmere Island, etc.) or very small ones (Buffalo Narrows, SK). An individual place may be identified in the literature as any one of: a band, a health unit, a health authority, a town, a settlement area, a health region, a province, or a geographic region requiring the inclusion of many terms in the filters.

Table 1 documents the results of the test searches. All of the filters retrieved more references than the standard

Table 1. Comparison of MeSH and filtered Ovid MEDLINE searches for publications related to Canadian Indigenous peoples by province or territory.

Province or territory	MESH search	Filter search	Difference (%)	Relevant of additional publications retrieved from the filter search (%)	Date searched
British Columbia	333	643	366 (110)	69	17 December 2013
Alberta	100	243	143 (143)	74	19 December 2013
Saskatchewan	137	231	118 (86)	77	17 December 2012
Manitoba	237	410	173 (73)	87	12 November 2013
Ontario	304	934	630 (207)	28	19 December 2013
Quebec	279	935	656 (235)	37	12 November 2013
New Brunswick	7	16	9 (128)	67	20 December 2013
Nova Scotia	15	27	12 (80)	92	12 November 2013
Newfoundland and Labrador	48	102	54 (112)	100	12 November 2013
Nunavut	82	463	381 (464)	83	11 December 2013
Northwest Territories	138	457	319 (231)	64	20 December 2013
Yukon Territory	19	82	63 (332)	83	20 December 2013

Note: Percentages were rounded to the nearest whole number. Prince Edward Island is not included because all combinations of terms relating to PEI and Indigenous peoples resulted in only two articles.

MeSH and geographic subject heading search. Increases in retrieval ranged from 73% to 464%. Relevance of the additional references ranged from 28% to 100%.

Discussion

Because these are first-generation search filters, they are subjectively developed and are not tested against an external gold standard. However, it is clear that all of the filters retrieved more studies related to Indigenous peoples' health than the MeSH terms alone and many of those additional results are relevant.

Given the limitations of the MeSH terms that are outlined in the Background section, it is not surprising that detailed search filters that use a combination of MeSH terms and text words retrieve additional relevant materials. The volume of relevant articles that are missed by standard indexing is noteworthy. Knowing that "conducting a thorough search to identify relevant studies is a key factor in minimizing bias in the review process" [16], searchers will be able to use these filters to more efficiently conduct comprehensive searches for articles about Indigenous peoples in Canadian provinces and territories.

Each of the filters is a unique balance of relevance and recall defined by the librarian who designed it and the filters reflect the nuances of the presence of Indigenous peoples in each province or territory. The filters have been constructed for practical use within the searchers' day-to-day work, with the understanding that they will be used in conjunction with other health concepts, so the balance between recall and relevance leans towards recall. All of the filters contain terms and names that currently retrieve zero results. This is a purposeful inclusion that anticipates that, with the increase in health research related to Indigenous Canadians, future studies may incorporate these terms.

Limitations of the filters

The filters have limitations. First, they are complex and if executed over slow connections, it may take a long time to complete their retrieval. Users working with slow connections may have to search sections separately to avoid time-out situations. Second, the filters are designed to retrieve articles that are relevant to the specific provinces and territories. However, many studies indexed in MEDLINE deal with the health of Indigenous peoples in Canada but give no indication of where those people reside. Many studies, particularly at the national scale include the phrase "Aboriginal, Métis, and Inuit" but do not supply precise geographic information. These cannot be captured by provincial and territorial filters. Third, groups of Indigenous peoples and even members of the same families are found in different provinces and territories. Traditional lands of specific groups often straddle borders. Because the filters retrieve studies based on jurisdiction, researchers studying large groups of people will find that they need to employ several of the filters to locate all studies relevant to one group of Indigenous peoples. Finally, none of the filters is perfect. They are being revised, refined, and rewritten as they are used. The

filters presented with this paper represent a snapshot, freezing the filters in time for the purpose of analysis.

Limitations of this study

This study itself has limitations. First, no attempt, apart from the sequence of steps described in the Methods section, was made to standardize the search development processes or styles of the searchers. Differences in relevance levels among the searches can be attributed to the differences in the searching styles, training, and experience of the different searchers. The study could be enhanced by having searchers test and review each other's filters. Second, these are first-generation filters; therefore, no gold standard was developed for precision or recall testing. Relevance testing was based on guidelines described in the Methods section, but even with guidelines the determination of relevance is a subjective act. Four different reviewers made determinations of relevance, so the relevance numbers should be read as indicative rather than absolute. Third, because the determination of relevance was based on the title and abstract rather than the full text, closer analysis of the texts could change the numbers of relevant studies.

Conclusion

This work is a first attempt at creating comprehensive filters to retrieve studies related to Indigenous peoples by Canadian province or territory in any subject area. The documentation of the challenges involved in creating filters for the Ovid MEDLINE database will be useful in creating similar filters in other subject areas and for other databases and platforms. These filters retrieve more studies related to Indigenous peoples in any province or territory than do the MeSH and geographic headings alone. The proportion of relevant studies among the additional studies retrieved varies. The filters demonstrate that if text-words are not included in searches for Indigenous people in Canada, many studies will be missed.

The filters continue to be refined and updated. Updated versions of the filters resulting from this project will continue to be published on the University of Alberta Libraries LibGuide, "[Health Sciences Search Filters](#)" and searchers are encouraged to look there for the most current versions. Searchers are encouraged to modify the filters for their own use and to incorporate local knowledge.

Future projects include rigorous testing of these filters, the creation of regional and national filters, and the creation of filters for other databases and platforms.

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References

1. Search Filters. Edinburgh, Scotland: Scottish Intercollegiate Guidelines Network (SIGN) [updated April 26, 2013; cited

- 27 January 2014] Available from: <http://www.sign.ac.uk/methodology/filters.html>.
2. Jenkins M. Evaluation of methodological search filters. *Health Information and Libraries Journal*, [Internet] 21 148–163, 2004. [cited 7 February 2014] Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1471-1842.2004.00511.x/pdf>.
3. Klatt MJ. An aid for total quality searching: developing a hedge book. *Bulletin of the Medical Library Association* [Internet]. 1994 [cited 7 February 2014] 82(10):438–41, Available from: <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC225972/pdf/mlab00109-0098.pdf>.
4. The Inter TASC Information Specialists' Sub-Group Search Filter Resource, [Internet] [cited 4 February 2014] Available from: <https://sites.google.com/a/york.ac.uk/issg-search-filters-resource/home>.
5. Pienaar E, Grobler L, Busgeeth K, Eisinga A, Seigfried, N. Developing a geographic search filter to identify randomised controlled trials in Africa: finding the optimal balance between sensitivity and precision. *Health Information and Libraries Journal*, [Internet]. 2011 [cited 7 February 2014] 28 210–215, Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1471-1842.2011.00936.x>.
6. Radut DS, Sanz-Valero, J. Developing and testing of search filters for the new European Union Member States' research. *Health Information and Libraries Journal*, [Internet] 27 227–234, 2010 [cited 4 February 2014] Available from: <http://onlinelibrary.wiley.com/doi/10.1111/j.1471-1842.2010.00903.x/pdf>.
7. Murray K. "[Filter] we're using to pull articles from PubMed for the Arctic health publications database". 20/06/2012; e-mail communication.
8. Sladek RM, Tieman JJ, Tyndall J, and Phillips, PA. Searching MEDLINE for Aboriginal and Torres Strait Islander health literature: questionable sensitivity. *Health Information and Libraries Journal*, [Internet]. 2013 [cited 7 February 2014] 30 138–148, Available from: <http://onlinelibrary.wiley.com/doi/10.1111/hir.12018/>.
9. *Aboriginal health search filter (HLWiki)* [Internet]. Vancouver, BC: HLWiki International; 2013 [updated July 8, 2013, cited 2 February 2014]. Available from: http://hlwiki.slais.ubc.ca/index.php/Aboriginal_health_search_filter.
10. Kelly L, St. Pierre-Hansen N. So many databases, such little clarity: searching the literature for the topic aboriginal. *Canadian Family Physician*, [Internet] 54: 1572–3.e5, 2008 [cited 4 February 2014] Available from: <http://www.cfp.ca/content/54/11.toc>.
11. Malyon R, Zhao Y, Oates B. Differences in the cost of admitted patient care for Indigenous people and people from remote locations. *Australian Health Review*. [Internet] 37 (1): 26–31, 2013. [cited 4 February 2014] Available from: http://www.publish.csiro.au/?act=view_file&file_id=AH11115.pdf.
12. Canada, National Household Survey. *Table 2: Number and distribution of the population reporting an Aboriginal identity and percentage of Aboriginal people in the population, Canada, provinces and territories, 2011*. [Internet]. Ottawa, Canada: Statistics Canada; 2011 [updated 24 April 2013; cited 4 February 2014]. Available from: <http://www12.statcan.gc.ca/nhs-enm/2011/as-sa/99-011-x/2011001/tbl/tbl02-eng.cfm>.
13. Mueller-Alexander J, Seaton HJ. Researching native americans: Tips on vocabulary, search strategies and internet resources. *Database*, [Internet]. 1994 17(2), 45–46. [cited 2 February 2014] Available from: <http://eric.ed.gov/?id=EJ481969>.
14. Campbell S, Tjosvold L, Dorgan M, and Behn-Smith, D. Finding Canadian Polar Indigenous studies in Medline, Cold Regions: Pivot points, focal points: Proceedings of the 24th Polar Libraries Colloquy; June 11–14, 2012; Boulder, Colorado. Boulder, Colorado: NSIDC; [Internet]. 2013. [cited 2 February 2014] Available from: <http://nsidc.org/pubs/gd/gd-34/PLC-24-proceedings-GD-34.pdf>.
15. Hobbema changes its name in the new year. *Edmonton Journal* [Internet]. 2013 December 25. [cited 7 February 2014] Available from: <http://www.edmontonjournal.com/technology/Hobbema+changes+name+year/9323420/story.html>.
16. Centre for Reviews and Dissemination. *Systematic Reviews: CRD's Guidance for Undertaking Reviews in Health Care Chapter 1. 3 Undertaking the Review*. 2009. [cited 4 February 2014] Available from: http://www.york.ac.uk/inst/crd/SysRev/SSL/!WebHelp/1_3_UNDER-taking_THE_REVIEW.htm.

FEATURE / MANCHETTE

A Commitment to First Nations Data Governance: A Primer for Health Librarians

Kevin Read, Gail Mc Donald, Brad Mackay, and Eugene Barsky

Canada, along with the rest of the world, is currently in the throes of an information and communications revolution that is having a transformative effect on our society. Deep conceptual changes have been enabled, accelerated, and influenced by dynamic new technologies. This revolution reflects both the technologies themselves and the massive amounts of data that tools now capture and process, whether the data relates to consumer behaviour or health care. Data are rapidly becoming a torrent of new information flowing into every area of the global economy, society, and culture [1]. Data are becoming increasingly important in health research, and First Nations health research specifically [2], as the ease of data sharing provides an opportunity for new levels of respect, transparency, and accountability that are transforming how Canadian First Nations health research is governed. The widespread use of data also yields new opportunities for First Nations communities who are exercising ownership of, and support principled access to, the data collected from health research in which they participate.

Late in 2013, Canada's research funding agencies, the Social Sciences and Humanities Research Council, the Natural Sciences and Engineering Research Council, the Canadian Institutes of Health Research, and the Canada Foundation for Innovation—collectively the TC3+, in collaboration with Genome Canada—joined forces to address the challenges of data management and sharing.

In the consultation document *Capitalizing on Big Data: Toward a Policy Framework for Advancing Digital Scholarship in Canada* [3], these Canadian funders try to find workable solutions for the challenges that data present. TC3+ plans to work with other organizations and working groups to ensure ongoing consultation and coordination with all stakeholders, including the provinces, in the development of Canada's national digital infrastructure for research.

Early in 2012, two groups emerged out of stakeholder concerns regarding the sustainability and future develop-

ment of Canada's advanced digital infrastructure ecosystem. The first was the Research Data Strategy Working Group, which morphed into Research Data Canada later that year [4]. It provides a forum for stakeholders to work together to enhance research data stewardship – the management, maintenance, and control of research data. The second was the Leadership Council for Digital Infrastructure [5], which focuses on the development of a national strategy to renew and strengthen Canada's advanced digital infrastructure ecosystem. Data management, sustainable funding, and integrated planning and sharing were identified as key issues to be addressed.

These developments are worth exploring in the context of Ownership, Control, Access, and Possession (OCAP), a set of principles that define how First Nations data can and should be used by researchers, governments, corporations, and other interested parties [6].

OCAP principles and the First Nations Information Governance Centre

The First Nations principles of OCAP originated in a 1998 brainstorming meeting of the National Steering Committee of the First Nations and Inuit Regional Longitudinal Health Survey. It was initially called "OCA"—for ownership, control and access—which served as an unintentional reminder of the Oka Crisis, a high-profile land dispute that took place in the summer of 1990 between Mohawk people and the town of Oka, Quebec. Not long after, when committee members recognized the importance of First Nations possessing their own data, the concept of data possession (and the subsequent letter "p") was added. OCAP as we know it was born.

OCAP was initially drafted to serve as a guide in the collection of data for the *First Nations and Inuit Regional Longitudinal Health Survey* and its eventual successor, the *First Nations Regional Health Survey* (FNRHS or RHS) [7], which collects information about health and wellness

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issues in 250 First Nations reserve and northern communities. In the 16 years since its inception the applications and scope of OCAP have grown significantly. From its successful application in First Nations communities across Canada to the trademarking of the “OCAP” name and the development of OCAP training workshops, OCAP reflects the commitment of First Nations people to the exercising of jurisdiction and governance over their own information.

The National Steering Committee eventually evolved into the First Nations Information Governance Committee, which operated at the Assembly of First Nations (AFN) and later received a mandate in 2009 from the AFN's Chiefs in Assembly to become the First Nations Information Governance Centre (FNIGC)—a federally incorporated, non-profit, First Nations entity founded in 2010 and based in Akwesasne, Ontario (with an office in Ottawa). In addition to serving as a home for OCAP, FNIGC administers two national surveys of First Nations communities: the RHS (which will enter its third cycle in 2014) and the First Nations Regional Early Childhood, Education and Employment Survey (FNREEES or REEES), which began initial deployment in the field in winter 2013 [7].

Though OCAP is relatively new, the ideas, themes, and values upon which it is built have existed among First Nations for generations. As such, it represents principles that are reflective of First Nations world views of jurisdiction, information governance, data protection, stewardship, and collective rights. OCAP has become synonymous with the best practices for how information about First Nations people should be gathered, stored, and accessed.

Ownership

The concept of data ownership is rooted in a First Nation community's relationship to its indigenous cultural knowledge. Much like how cultural knowledge is “owned” collectively, a community or group must own its information collectively—in the same way that individuals can expect to own their personal information.

Control

This principle asserts that First Nations people, their communities, and representative bodies must control how information about them is collected, used, and disclosed. The element of control extends to all aspects of information management, from collection of data to the use, disclosure, and protection of data.

Access

This principle refers to the concept that First Nations must have access to information and data about themselves and their communities, regardless of where it is held. This also refers to the right of First Nations communities and organizations to manage and make decisions regarding who can access their collective information.

Possession

This principle puts data within First Nation jurisdiction and therefore within First Nation control. Although ownership identifies the relationship between a people and their information in principle, possession (or stewardship) is more concrete. It refers to the physical control of data. First Nations generally have little or no control over data that are in the possession of others, which is why possession is a critical element of OCAP.

The need for a set of data governance principles and guidelines specific to First Nations is rooted in a decades-long history of unethical and disrespectful information gathering in First Nations communities. The final report of the landmark Royal Commission on Aboriginal Peoples addressed this issue directly:

“In the past, Aboriginal people have not been consulted about what information should be collected, who should gather that information, who should maintain it, and who should have access to it. [...] Because data gathering has frequently been imposed by outside authorities, it has met with resistance in many quarters.” [8]

Because the majority of researchers looking to collect data have traditionally been non-Aboriginal, a sense of distrust developed in First Nations communities. Examples of the misuse of First Nations information, particularly health information, are widespread. Misuse ranges from a researcher at the University of British Columbia who used unapproved blood samples from the Nuuchah-nulth First Nation under the auspices of a Health Canada study of rates of arthritis in the early 1980s [9] to Arizona State University researchers in the 1990s who gathered community health information taken from the Havasupai Tribe purportedly for a study of diabetes—only to use the information later to support published research on in-breeding, anthropological migration patterns, and schizophrenia [10].

An especially troubling example of poor information governance involves Health Canada's Non-insured Health Benefits Database (NIHB), which holds a significant amount of information about First Nations use of health services and goods such as prescription drugs, medical transportation, dental care, and medical devices. In 2001 Health Canada gave NIHB data about comprehensive pharmacy claims to Brogan Inc., a US-based health consulting and analysis firm, which in turn offered to sell the data to pharmaceutical companies for their own research. Health Canada removed personal identification information from the NIHB data but community identifiers remained. First Nations communities were not consulted or advised about the data transaction until 2007 when Health Canada advised the Assembly of First Nations about the extension of the Brogan contract [11]. Those involved in this disclosure were surprised that First Nations would be concerned about the release and eventual commercial use of their data.

Based on these and other precedents it became clear to many First Nations people and communities that government officials, researchers, academics, and corporations may not understand or support their interests. That is

why OCAP was born and why it has flourished in the years since.

OCAP is currently housed and overseen by the FNIGC, which continues to apply the principles in the implementation of its two national survey initiatives, the RHS and REEES, which are carried out among 30,000 respondents in 10 regions across the country in collaboration with regional First Nations partners. The key to FNIGC's success is rooted in its adherence and respect of OCAP, which has come to represent the benchmark for ethical information collection and protection in First Nations communities.

In a response to increased interest in OCAP, FNIGC has also begun offering OCAP workshops (OCAMP) that give First Nations people the tools they need to implement OCAP in their communities and local governments. In 2014 it will also introduce a certification process where interested parties can apply for OCAP certification.

With OCAP, the FNIGC emphasizes the need to (i) develop clear research and data sharing agreements and set standards to ensure the protection and integrity of First Nations health data, (ii) organize data in a way that can be available and understood by others, and (iii) feel confident that this data will not be mismanaged so that their community can make decisions to inform future health research [6]. Other examples of developing data standards and policy for First Nation individuals are the British Columbia (BC) Tripartite Data Quality and Sharing Agreement (TDqSA) [12] and the Panorama Project [2]. The TDqSA promotes the sharing of First Nations health data among federal, provincial, and First Nations governments to improve the management of health data and enhance the delivery of health services, whereas the Panorama Project is a software system that promotes up-to-date, high quality health data that are owned and operated by BC First Nations [13]. These efforts safeguard against any data being reported or analyzed without the consent of those in charge of First Nations data. The TDqSA promotes collaboration between First Nations and Canadian governing bodies to ensure that BC First Nations exercise ownership of their data and participate in the decision making process for the future use of the data. The OCAP principles are echoed by Joshua Tauberer, [14] who addresses 17 key principles to sharing open government data including timeliness, accessibility, provenance, and trust to promote the transparency, integrity, and rightful ownership of research data. These principles are essential for establishing an open model with respect to data creation and sharing in both government and health care settings.

Generally, for open data sharing to work effectively, data made publicly accessible must be comprehensible to anyone, whether experienced researcher or member of the public, so that it can be interpreted and evaluated. Sharing data is an important factor in the promotion of both data quality [15] and documentation of the provenance and integrity of the data over time [16–18]; if data are to be shared, it places the onus on those responsible for creating the data to be transparent and ensure that the data are collected ethically and according to their stated research methods. A key component of data sharing and the open data movement is to ensure that personally identifiable

information is kept private by managing and documenting consent, safeguarding and controlling access to personal data, and ensuring the protection and accountability of personal health data [19]. These rules should be followed for all data that are collected from human subjects, so that incidents like those between First Nations communities and the NIHB can be avoided.

Where do librarians fit in?

Librarians have been long time advocates of the provision of access to timely, trusted, high quality information, and transitioning into the realm of research data represents the field's next logical step forward. To achieve the level of transparency, integrity, and quality that is compulsory for sharing data collected from health sciences research requires the expertise of information professionals who can support the collection, organization, management, and storage of these data. Librarians have been revamping [20, 21] their current services and knowledge bases to address the data management needs of their user groups to collect, organize, and preserve health research data [22]. The management and organization of research data are aligned with traditional library roles of collection development, providing reference services [23], and increasingly as embedded librarians [24–26] working alongside researchers to assist with information management. Librarians' expert knowledge of description, indexing, metadata, and digital library management further sets the stage for participation in data management and sharing efforts [20]. Assisting researchers to assign metadata descriptors to data, organize data produced from a research study, and catalogue data for discovery and interpretation in the future, are all examples of ways librarians can support data management. Finally, experiences with collection management and digital storage have afforded librarians with opportunities to expand their roles and turn into "data brokers," [27] where they appraise and store data within institutional repositories or data warehouses. This experience and expertise places librarians and libraries at the forefront for supporting health researchers in the open data initiative.

Canadian health sciences librarians are well positioned to support data storage and access of health research data through platforms such as the Canadian Virtual Health Library, which could expand its current list of health information resources to include research data repositories. Additionally, the Canadian Health Libraries Association and its provincial Chapters (e.g., Health Libraries Association of BC, Northern Alberta Health Libraries Association) can further their existing efforts to support health care research by advocating OCAP principles in the management and storage of health research data involving First Nations communities. Many libraries now provide instruction to researchers on the topics of data literacy, management, and preservation; these teaching models can be adjusted to recognize the unique needs of First Nations communities as owners and stewards of their own health data [28–31].

It is our role as information experts to step up and adapt to the new opportunities that data provide, and nowhere is this role more important than in the realm of health sciences research. In the health sciences, it is crucial that

data be transparent, comprehensible, accessible, and protected so that First Nations communities, health researchers, and individuals participating in health research can prevent the misuse of data in the future.

References

1. Byers AH, Manyika J, Chui M, Brown B, Bughin J, Dobbs R, et al. *Big data: The next frontier for innovation, competition, and productivity*. McKinsey Global Institute; 2011. 156 p.
2. First Nations Health Council. 2013 Guidebook: Building Block for Transformation [Internet]. First Nations Health Authority. 2013. [cited 16 January 2014]. Available from: http://www.fnhc.ca/pdf/2013_Guidebook.pdf.
3. Capitalizing on Big Data: Towards a Policy Framework for Advancing Digital Scholarship in Canada [Internet]. Government of Canada. 2013 Oct 16 [cited 16 January 2014]. Available from: http://www.sshrc-crsh.gc.ca/about-au_sujet/publications/digital_scholarship_consultation_e.pdf.
4. Research Data Canada [Internet]. Ottawa (ON): Government of Canada. 6 Dec 2012 [updated 14 Jan 2014; cited 16 Jan 2014]. Available from: <http://rds-sdr.cisti-icist.nrc-cnrc.gc.ca/eng/>.
5. Leadership Council. Advancing Canada's Digital Infrastructure [Internet]. Ottawa (ON): Leadership Council for Digital Infrastructure. 2013 [cited 20 Jan 2014]. Available from: <http://digitalleadership.ca/>.
6. First Nations Centre. OCAP: Ownership, Control Access and Possession [Internet]. Ottawa (ON): National Aboriginal Health Organization; Sanctioned by First Nations Information Governance Committee, Assembly of First Nations. 2007 [cited 16 January 2014]. Available from: <http://cahr.uvic.ca/nearbc/documents/2009/FNC-OCAP.pdf>.
7. First Nations Regional Health Survey [Internet]. Ottawa (ON): First Nations Health Council. 2011 [cited 20 January 2014]. Available from: http://www.fnhc.ca/index.php/initiatives/research_and_data/regional_health_survey.
8. Report of the Royal Commission on Aboriginal Peoples [Internet]. Ottawa (ON): Government of Canada. 2011 Nov 15 [cited 5 Jan 2014]. Available from: http://www.collectionscanada.gc.ca/webarchives/20071115053257/http://www.ainc-inac.gc.ca/ch/rcap/sg/sgmm_e.html.
9. Dalton R. Tribe blasts 'exploitation' of blood samples. *Nature*. 2002;420(11). doi: 10.1038/420111a.
10. Drabiak-Syed K. Lessons from Havasupai Tribe v. Arizona State University Board of Regents: Recognizing Group, Cultural, and Dignitary Harms as Legitimate Risks Warranting Integration into Research Practice. *J Health Biomed Law*. 2010;6(2):175–226.
11. Dumas A, Chapman M (Assembly of First Nations, Ottawa, ON). Data Sharing Agreement: First Nations Inuit Health Branch (FNIHB) and Brogan Consulting Inc. Winnipeg (MB): Annual General Assembly (CAN); 2010 Jul. 3 p. Resolution No.: 30/2010.
12. B.C. Tripartite Framework Agreement on First Nation Health Governance [Internet]. Tripartite Committee on First Nations Health Annual Report. Tripartite First Nations Health Plan. 2012–2013 [cited 30 December 2013]. Available from: <http://www.health.gov.bc.ca/library/publications/year/2013/Together-in-Wellness.pdf>.
13. Mallory K. BC First Nations Panorama Implementation Project. Tripartite First Nations Health Plan. 2010.
14. Tauberer J. Open Government Data. Civic Impulse LLC; 2012.
15. Giarlo MJ. Academic Libraries as Data Quality Hubs [Internet]. State College, PA; 2012 [cited 2 January 2014]. p. 1–20. Available from: <https://scholarsphere.psu.edu/files/g732d898n>.
16. Piwowar H, Vision TJ. Data reuse and the open data citation advantage. *PeerJ* [Internet]. 2013 [cited 25 January 2014]. 1(1). Available from: <https://peerj.com/preprints/1.pdf>.
17. Tenopir C, Allard S, Douglass K, Aydinoglu AU, Wu L, Read E, et al. Data sharing by scientists: practices and perceptions. *PLoS One* [Internet]. 2011 Jan [cited 27 Feb 2013]; 6(6):e21101. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3126798&tool=pmcentrez&rendertype=abstract>.
18. Royal Society. Science as an open enterprise. London (UK): The Royal Society Policy Centre; 2012. 104 p.
19. Canadian Institutes of Health Research. CIHR Best Practices for Protecting Privacy in Health Research [Internet]. Government of Canada. Ottawa (ON); 2005 [cited 15 January 2014]. Available from: <http://www.cihr-irsc.gc.ca/e/29072.html>.
20. Cox A, Verbaan E, Sen B. Upskilling Liaison Librarians for Research Data Management. *Ariadne A Web Print Mag. Internet Issues Libr. Inf. Spec.* 2012;(70).
21. Auckland M. Re-skilling for Research. Research Libraries UK [Internet]. 2012 [cited 14 Jan 2013]. Available from: <http://www.rluk.ac.uk/wp-content/uploads/2014/02/RLUK-Re-skilling.pdf>.
22. Salo D. Retooling Libraries for the Data Challenge [Internet]. *Web Mag. Inf. Prof.* 2010 [cited 9 Nov 2012]. Available from: <http://www.ariadne.ac.uk/issue64/salo>.
23. Carlson J. Demystifying the data interview: Developing a foundation for reference librarians to talk with researchers about their data. *Ref. Serv. Rev.* [Internet]. 2012 [cited 25 Apr 2013]; Available from: http://docs.lib.purdue.edu/cgi/viewcontent.cgi?article=1186&context=lib_research.
24. Covert-Vail L, Collard S. New Roles for New Times: Research Library Services for Graduate Students [Internet]. Washington (D.C); 2012 [cited 9 January 2014]. Available from: <http://www.arl.org/storage/documents/publications/nrnt-grad-roles-20dec12.pdf>.
25. Tan MC, Maggio LA. Expert searcher, teacher, content manager, and patient advocate: an exploratory study of clinical librarian roles. *J. Med. Libr. Assoc.* [Internet]. 2013 Jan [cited 27 Feb 2013];101(1):63–72. Available from: <http://www.pubmedcentral.nih.gov/articlerender.fcgi?artid=3543140&tool=pmcentrez&rendertype=abstract>.
26. Borgman CL. Research Data: Who will share what, with whom, when, and why? *China-North Am. Libr. Conf.* [Internet]. Beijing; 2010 [cited 11 Jan 2013] 21. Available from: <http://works.bepress.com/borgman/238/>.

27. Borchert M, Bradbury S, Broadley P. Collaborating to develop research data management services and collections [Internet]. 2013 [cited 23 Apr 2013]. Available from: http://eprints.qut.edu.au/59211/2/PRES_IATUL_2013_Borchert_Bradley_Broadley_DataMgt_FINAL.ppt.
28. Creamer A. Creating an Online Research Data Management Course: A Conversation with Data Librarians Robin Rice and Stuart Macdonald [Internet]. Worcester (MA); 2011 [cited xxx xxxx xxxx]. Available from: http://esciencelibrary.umassmed.edu/rice_macdonald_interview.pdf.
29. Piorun M, Kafel D, Leger-Hornby T, Najafi S, Martin E, Colombo P, et al. Teaching Research Data Management: An Undergraduate/Graduate Curriculum. *J. eScience Lib.* [Internet]. 2012 [cited 14 January 2014]. 1(1):46–50. Available from: <http://escholarship.umassmed.edu/jeslib/vol1/iss1/8/>.
30. Johnston L, Lafferty M, Petsan B. Training Researchers on Data Management: A Scalable, Cross-Disciplinary Approach. *J. eScience Lib.* [Internet]. 2012 [cited 8 Nov 2012];1(2). Available from: <http://escholarship.umassmed.edu/jeslib/vol1/iss2/2/>.
31. Smylie J, Anderson M. Understanding the health of Indigenous peoples in Canada: key methodological and conceptual challenges. *Can Med A.J.* [Internet]. 2006 Sep 12 [cited 20 Jan 2014];175(6). Available from: doi: 10.1503/cmaj.060940.

Sharing What we Know About Living a Good Life: Indigenous Approaches to Knowledge Translation

Janet Smylie, Michelle Olding, and Carolyn Ziegler

Abstract: Knowledge Translation (KT), a core priority in Canadian health research, policy, and practice for the past decade, has a long and rich tradition within Indigenous communities. In Indigenous knowledge systems the processes of “knowing” and “doing” are often intertwined and indistinguishable. However, dominant KT models in health science do not typically recognize Indigenous knowledge conceptualizations, sharing systems, or protocols and will likely fall short in Indigenous contexts. There is a need to move towards KT theory and practice that embraces diverse understandings of knowledge and that recognizes, respects, and builds on pre-existing knowledge systems. This will not only result in better processes and outcomes for Indigenous communities, it will also provide rich learning for mainstream KT scholarship and practice. As professionals deeply engaged in KT work, health librarians are uniquely positioned to support the development and implementation of Indigenous KT. This article provides information that will enhance the ability of readers from diverse backgrounds to promote and support Indigenous KT efforts, including an introduction to Indigenous knowledge conceptualizations and knowledge systems; key contextual issues to consider in planning, implementing, or evaluating KT in Indigenous settings; and contemporary examples of Indigenous KT in action. The authors pose critical reflection questions throughout the article that encourage readers to connect the content with their own practices and underlying knowledge assumptions.

Introduction

The emergence of Knowledge Translation (KT) as a health research, policy, and practice priority in Canada is strongly linked to the creation and initial mandate of the Canadian Institutes of Health Research (CIHR) in 2000. This initial aim of the CIHR was to excel not only in the creation of new knowledge but also to ensure that this knowledge was “translated” from the research setting into “real-world applications to improve the health of Canadians, provide more effective health services and products, and strengthen the health care system” [1, 2]. The CIHR originally defined KT as “the exchange, synthesis and ethically sound application of knowledge—within a complex system of interactions among researchers and users—to accelerate the capture of the benefits of research for Canadians through improved health, more effective services and products, and a strengthened health care system” [2].

In subsequent years, definitions and models of KT have expanded rapidly, extending from research-embedded conceptualizations to program- and service-based activities [3].

There is currently no clear consensus in the literature regarding what KT is and which models and strategies are the most effective. There is some convergence in the recent literature about the effectiveness of participatory KT processes that attempt to understand and address the context in which KT is taking place and to bridge some type of “know–do gap” [4]. Health librarians have highlighted the critical role existing human information services (i.e., reference librarians, pharmacists, patient education specialists) already play in linking knowledge sources to knowledge users and the synergies that can be gained by building on and expanding these roles [3].

Indigenous scholars and communities across Canada have been active—if at times reluctant—participants in this burgeoning KT movement, working to ensure that Indigenous people, their needs, and their potential contributions were taken into account [5]. The lead author (JS) has had the opportunity to be involved in bridging conversations regarding KT and Indigenous community knowledge systems since the initial CIHR consultations including a CIHR led KT workshop in June 2002 and early funding initiatives. Ironically, a common initial response

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when she started talking about KT in diverse Indigenous communities was that mainstream conceptualizations of KT were hard to make sense of and did not appear to be practically relevant. As the conversations deepened it became evident that KT was nothing new for Indigenous peoples. In contrast to the evolution of European knowledge and knowledge systems that has resulted in a separation of knowledge production from knowledge use, in Indigenous contexts knowledge is almost always inextricably linked to action both philosophically and practically.

There are distinct understandings of knowledge and unique, diverse, and contextually specific knowledge sharing processes found in Indigenous communities. Ideally, efforts to support KT in Indigenous contexts would build on local Indigenous languages and existing knowledge conceptualizations, sharing systems and protocols. Indigenous communities have identified a strong preference for approaches to KT that draw on Indigenous ways of knowing and doing [5–7]. Such approaches have also been demonstrated to be practically effective across diverse Indigenous communities [8]. These demonstrations build on the much broader literature regarding the importance of knowledge, attitudes, and beliefs to health learning and behaviour change. Clearly, messages, mediums, and practices that demonstrate socio-cultural congruency (i.e., draw on local cultural knowledge, attitudes, and belief systems) will have better uptake. This is especially important for Indigenous people and communities where a big part of colonial policy has been premised on the marginalization and devaluing of Indigenous ways of knowing and doing [9].

Our aim in this article is to provide relevant information that will enhance the ability of readers from diverse backgrounds to promote and support Indigenous KT efforts (i.e., KT processes that build on Indigenous understandings of knowledge and Indigenous approaches to knowledge sharing). Each section features critical reflection questions that we hope will challenge the reader to bridge the content of this article to their own underlying knowledge assumptions and practices.

Indigenous knowledge(s), knowledge systems, and KT

Critical reflection questions: What assumptions do I make about what constitutes valid and useful knowledge? How do these assumptions fit or not fit with the ideas about Indigenous knowledge and knowledge systems described in this section?

As alluded to above, KT scholarship and practice in Canada has emerged within the context of university- and hospital-based health sciences research, a knowledge system in which the domains of research and action–practice have largely been kept separate [10]. It is important to recognize that Indigenous knowledge systems and KT practices are rooted in a very different linguistic, cultural, social, political, and historic context. Not surprisingly given these differences, mainstream KT theoretical models and proven practices may fall short in Indigenous contexts.

Understanding the differences and similarities in the root epistemologies of academic health sciences and Indigenous community knowledge systems is a key step in supporting the development and implementation of KT strategies that are relevant and useful to Indigenous peoples. An epistemology is a theory of knowledge that sets out what constitutes knowledge and how we come to know. Academic health sciences have emerged from positivist thought traditions in which the goal of knowledge production is to search for general laws or principles through “objective” observation. Within the positivist tradition, knowledge is that which can be quantified and counted and is thought to exist independent of the people or places from which it emerges [11]. Health sciences knowledge production is characterized by knowledge specialization and academic silos, meaning that KT is typically conceptualized as the translation of expert knowledge from researcher to health care practitioners [10].

Indigenous knowledge systems have underlying epistemologies that are distinct from those of academic health sciences [12, 13]. Indigenous epistemologies, for example, almost always intrinsically connect knowledge with action. For an individual to hold knowledge and not apply it in their life or share it for the benefit of the collective could be seen as foolish and selfish from an Indigenous perspective. Knowledge may be considered as pre-existing such that there are no new “discoveries” but rather a process of gradual awareness and understanding of complex, interconnected, and pluralistic systems of existing knowledge. In this way, knowledge development work is actively transformative as it is linked to life-long processes of human development. Stories themselves can be perceived as holding “medicine” and the process of sharing stories as acts of healing.

Another foundational element of many Indigenous knowledge systems is that the inter-relationships between perceived elements are considered equally or more important than the nature of the perceived elements themselves. For example, in considering physical health, it would be important to consider not only physical health alone but also physical health in relation to mental, emotional, and spiritual health; family, community, nation; land and the local eco-system; and kin relations past, present, and future.

The importance of inter-relationality extends to the conceptualization of the individual in relation to the collective. For many Indigenous people, notions of identity, health, rights, and freedoms are rooted in the collective. The health needs of the family or community may take precedence over individual health needs. Likewise land, material goods, or information may be seen as primarily a collective rather than individual resource. This contrasts with euro-western concepts of self and individual rights and freedoms [14].

With these considerations in mind, KT in Indigenous contexts could be understood as “Indigenously led sharing of culturally relevant and useful health information, and practices to improve Indigenous health status, policy, services, and programs” [15] or more simply as “Sharing what we know about living a good life” [15]. Indigenous processes of sharing and applying knowledge

have always been an essential and embedded part of Indigenous civilizations [16]. Indigenous KT strategies and protocols are commonly dynamic, participatory, integrated into family and community activities, repeated or cyclical, and intergenerational [15]. A reliance on the land for sustenance translated into the need for sophisticated understandings of and relationships with local ecosystems. As such, experiential demonstration and practice in real life situations were common Indigenous KT approaches for this type of knowledge [15–17]. Storytelling is another core Indigenous KT strategy, particularly common for the intergenerational transfer of knowledge.

It is important to keep in mind that in this section we introduced only a few overly simplified characteristics of Indigenous knowledge, knowledge systems, and KT. The actual diversity and complexity of Indigenous knowledge could be paralleled to the diversity and complexity of the vast landscapes of the Americas (to which it is heavily tied). There is no one-size-fits-all model for what KT should look like, given the diversity of knowledge sharing practices across communities. Likewise, our portrayal of academic health sciences has not included the modern and post-modern integration of social sciences and the increasingly complex interdisciplinary paradigms currently in use. Our comparisons have highlighted tensions because knowing and understanding difference can be a useful starting point in contexts where differences have been previously ignored or overlooked. However, although Western and Indigenous systems of knowledge and knowledge dissemination have many differences, the two are not entirely irreconcilable [18].

Currently though, most health science KT efforts have been modelled on the one-way transfer of academic health knowledge into Indigenous communities, often with little consideration of pre-existing Indigenous knowledge systems. This external imposition of one knowledge system onto another, although often done with good intentions, is almost always ineffective, especially when there are key theoretical and practical tensions. Indigenous scholar and elder Leroy Littlebear described this process as “jagged worldviews colliding” [19]. For Indigenous individuals and communities, such one-way KT processes may resonate with historic and current colonial practices such as the apprehension of Indigenous children into residential schools, where there was a subsequent one-way transfer of European-based language and schooling or the imposition of European systems of law and land rights into Indigenous communities through the Indian Act and other colonial legislations. The fundamental rights of Indigenous self-determination at the individual and collective levels include not only land rights but also the right to “construct knowledge in accordance with self-determined definitions of what is real and what is valuable” [14]. The development and application of Indigenous KT models is therefore not only practical but also integral to processes of decolonization and healing.

Moving towards KT models that embrace diverse understandings of knowledge and recognize, respect, and build on existing knowledge systems will not only result in better processes and outcomes for Indigenous communities, it will also provide rich learning for mainstream KT

scholarship and practice. In the following section we will examine some key contextual issues that should inform the development of KT strategies in Indigenous settings. Keep in mind that many of these issues may also be relevant more broadly.

Important contextual issues to consider when planning, implementing, and (or) evaluating knowledge sharing activities in Indigenous contexts

Critical reflection questions: What do you know about the Indigenous peoples and communities in the geographic area where you live and work? From what sources is this knowledge drawn? Can you identify knowledge gaps and strategies to address these gaps in your personal understanding and knowledge? Which of the contextual issues listed do you think are relevant for your life and work with Indigenous individuals and communities? Which issues are relevant to your work more generally?

Cultural safety

There are many reasons why Indigenous community members may not feel comfortable or safe in non-Indigenous institutional contexts, including libraries. These can include historic and current individual and systemic level experiences of abuse, discrimination, and racism. The term “cultural safety” originated in New Zealand in response to dissatisfaction of Maori people with their nursing care. The nursing council of New Zealand had defined culturally unsafe care as “any actions that diminish, demean or disempower the cultural identity and wellbeing of an individual” [20]. The meaning and application of the term cultural safety is evolving in Canada; however, it is commonly perceived as an advancement beyond “cultural sensitivity” [21]. Cultural safety is usually defined by clients themselves, with the onus placed on health care professionals to self-reflect and work with their institution to address the impact of power imbalances, attitudinal, and institutional discrimination and colonization on service provision and client–provider relationships. This work can be particularly challenging given the pervasive negative representations of Indigenous people in the media and education systems.

Underlying unmet material, social, and health needs

The historic and current unequal distribution of health and social resources has translated into a disproportionate burden of poverty, food insecurity, homelessness and housing inadequacy, unemployment, and lower formal educational achievement for Indigenous people in Canada. Linked to these challenges in the social determinants of health are striking disparities in the health status of Indigenous peoples compared with the general Canadian population [22]. For example, diabetes and mental illness are much more common among First Nations populations compared with non-First Nations populations [23, 24]. It is important to understand that these unmet needs and high illness burdens can interfere with participation in learning, teaching, and participation in health information sharing events and programs.

Health literacy

The Canadian Expert Panel on Health defines health literacy as “The ability to access, understand, evaluate and communicate information as a way to promote, maintain and improve health in a variety of settings across the life-course” [25]. Although little information regarding the health literacy of Indigenous peoples in Canada is available, we do know that this population faces a disproportionate burden of low literacy with respect to reading and writing in English compared with non-Indigenous communities as well as much lower rates of high school completion [26]. Indigenous-specific models of literacy also exist and are notable for their holistic understandings and approaches. The Rainbow/Holistic Approach to Aboriginal literacy, as one example, uses seven ways of knowing, each corresponding to a color and recognizes that spirit, heart, mind, and body equally contribute to a life of balance and nurtures them all [27].

Protection and custodianship of Indigenous knowledge

Colonization included the purposeful undermining of Indigenous languages and culture, commercialization of Indigenous art, and appropriation of Indigenous plant knowledge in the development of medicine, all without consent, acknowledgement, or benefit to Indigenous peoples [28]. Current legal regimes are still inadequate to protect Indigenous knowledge [28]. Within the context of Indigenous health and health information there are also examples of historic abuses and inequities in Canada, including nutritional experimentation on Indigenous children in residential schools and the exclusion of Indigenous communities from national health surveys. Not surprisingly given this history, many Indigenous communities are very concerned about external to community ownership, control, and access to and use of their health information and therefore have created policies and processes to ensure Indigenous governance and management of Indigenous health information [29].

Publication bias

The large majority of published health information has been created without taking Indigenous ways of knowing, doing, and sharing information into account. This literature is commonly perceived in Indigenous contexts as not immediately useful or relevant and, at worst, as a continuing colonial imposition of external ways of knowing upon Indigenous people. There is a deficit of Indigenous-led, Indigenous-authored, and community-relevant published materials. A large proportion of that which exists is in the form of “grey” literature (i.e., non-indexed publications). When Indigenous scholars and communities produce materials for non-Indigenous specific scholarly journals there is usually a tension between the defined criteria of what is acceptable in peer-reviewed publications and what might be perceived as relevant and linked to Indigenous ways of knowing and doing. This divergence means that articles that take Indigenous constructions of knowledge into account may be less likely to be published. For example, an editor may prioritize generalizability but Indigenous communities may want emphasis on the uniqueness of their particular context.

Reciprocity in relationships

Reciprocity is a foundational social and spiritual principle for many Indigenous communities that, according to Cree philosopher Willie Ermine, “dictat[es] how all life would co-exist in mutual protection, benefit, and continuity” [30]. Within the academic context this may emerge as a two-way teaching and learning process in which the dichotomy between “teacher” and “learner” is challenged, and the faculty members make extra efforts to be accessible and equally vulnerable in the knowledge relationship [31].

Location

A significant proportion of Indigenous people in Canada live in remote and rural areas where geographic location can limit access to infrastructure commonly taken for granted, such as high speed internet access, tertiary healthcare facilities, and public libraries. The majority of Indigenous people now live in urban areas in Canada and this population is rapidly increasing. Urbanization unfortunately does not necessarily translate into improved health or living conditions for Indigenous populations [23, 32, 33]. In cities, the Indigenous population may be more dispersed and diverse compared with more rural or remote settings.

Table 1 summarizes these specific strategies for implementing KT activities in Indigenous contexts.

Indigenous knowledge translation in contemporary contexts—a few examples

Critical reflection questions: Can you identify how these examples have incorporated Indigenous understanding of knowledge and Indigenous approaches to KT? Do they address the contextual issues identified in the previous section? Do you see them as valid examples of KT? Why or why not?

What follows is by no means meant to be comprehensive, we have simply selected a few examples from diverse settings. The lead author is currently in the process of building a more comprehensive listing of Indigenous KT initiatives that will be shared on an interactive web page. Please contact her if you have a good example that you would like to see included.

Maria Campbell's Halfbreed Ball

On 15 June 2013 as part of the Native American and Indigenous Studies Association Conference, held in Saskatoon, Saskatchewan, Métis elder, author, and community activist Maria Campbell organized an evening of food, dance, art, and entertainment. The Halfbreed Ball was fashioned on historic Métis social events that were held to honour the arrival and departure of visitors to Métis communities—times when the word Halfbreed was used with pride. The ten-course meal featured traditional foods served with a contemporary flair (Figure 1). Between courses, guests were treated to a parade of historic Métis fashion, poetry, fiddle music and jiggling, and folk and opera singing. This was followed by an old-time dance. In the words of one guest “this evening...made abundantly clear the continuity of this lively culture and the warm, open-hearted nature of those Métis well-grounded in and proudly contributing to the vitality of the culture today” (Susan

Table 1. Contextual Issues for KT in Indigenous Contexts and Mitigating Strategies

Contextual issue	Mitigating Strategies
Cultural safety	<p>Critically reflect on your own knowledge, values, assumptions, and experiences generally with respect to the social hierarchies around class, age, ability, gender, sexual orientation, race and ethnicity, and more specifically with respect to Indigenous peoples.</p> <p>We almost all have bias and prejudicial assumptions; can you identify any of yours? Are there particular populations groups where you are less knowledgeable, less comfortable, or more judgemental? How has the media and your education shaped your views?</p> <p>Fill the gaps and (or) identify populations or groups for which you might need to do some more critical self-reflection to contribute to safe and respectful interactions.</p> <p>Identify allies in your institution and within your communities of practice and work together to identify and address institutional barriers and increase institutional safety.</p> <p>Search for institutional best practices that might be relevant to your place of work.</p>
Health literacy	<p>Learn more about Indigenous conceptualizations of literacy and health literacy [27].</p> <p>Think broadly about literacy, (i.e., reading and writing in English is one aspect that is important in most mainstream institutional contexts) but what about the importance of traditional local ecologic literacies in a remote wilderness setting?</p> <p>Strategize with others on how your institution could support diverse knowledge users to obtain an enhanced health literacy.</p> <p>Co-create plain language summaries.</p> <p>Assess and respond to opportunities to build capacity and literacy using health information technologies.</p>
Protection and custodianship of Indigenous knowledge	<p>Critically examine information sources with an eye towards authenticity of authorship, Indigenous community involvement, and custodianship of Indigenous information and the prevention of appropriation.</p> <p>Support and participate in processes that actively promote Indigenous community production and management of Indigenous health information and health information systems.</p> <p>In situations where it appears a person external to the community is publishing or sharing Indigenous community health information with no apparent community involvement, ask questions.</p>
Underlying unmet material, social, and health needs	<p>Ensure that projects and events involving Aboriginal community members include budgets for transportation allowance and childcare. Provide healthy food at events and meetings.</p> <p>Ensure schedules fit with the needs of those who are experiencing chronic illnesses.</p> <p>Allow for flexibility in scheduling to account for personal, family, and community illness or crisis.</p>
Publication bias	<p>Include grey literature and oral histories in your literature searches and indexes.</p> <p>Recognize and value multiple forms of knowledge dissemination.</p> <p>Consider incorporating equity criteria in your critical appraisal methods [34].</p> <p>Be aware that search terms in use do not always match the terms by which Indigenous people self-refer; this can be problematic, both with the use of search terms that are considered offensive by some people (i.e., Indians, Eskimos) and also the non-specificity of terms now in more current use by Indigenous people (i.e., the term Indigenous).</p> <p>Support Indigenous and community led publication efforts.</p>
Reciprocity in relationships	<p>Ensure that the KT project or activity will be mutually beneficial to all parties, including Indigenous community partners.</p> <p>For those in a role that may involve structured social privilege (i.e., health professional, librarian, academic faculty) make efforts to bridge relationships and build trust by sharing your own hopes, fears, and vulnerabilities in the learning relationship.</p> <p>Create opportunities for Indigenous community capacity building and recognize that capacity building will be a two-way process (i.e., partners external to Indigenous community will also be gaining capacities and training in working with Indigenous communities).</p>
Location	<p>When working with Indigenous peoples from a location that is different from where you live and work, ideally try and spend time in this place with a knowledgeable and willing community member who is being compensated for orienting you.</p> <p>Working with Indigenous community partners, actively reflect on what is unique about the context and location where the KT activity is taking place.</p> <p>Consider outreach strategies in urban areas.</p>

Fig. 1. Author Janet Smylie serving traditional food and Rajan Anderson playing fiddle at the Halfbreed Ball, Native American and Indigenous Studies Association conference, June 2013.



Gingell, written communication, 2013). This event exemplifies experiential, socially embedded Indigenous KT, which in this case showcased historic and contemporary Métis culture to Indigenous scholars from around the world.

The Native Youth Sexual Health Network (NYSHN)

The NYSHN is an organization engaged in KT around Indigenous youth sexual and reproductive well-being. Led by Indigenous youth, NYSHN encompasses a peer-based network of advocates, families, and communities [35]. The network collaborates on various initiatives that support Indigenous youth in sharing their own knowledge on healthy sexuality, as well as mobilizing collective action around youth-identified priorities. Some recent initiatives include a national gathering for Indigenous young women, a “sexy health” carnival, and a participatory action research project exploring the role of land in the sexual health of Metis women and youth [35]. KT, in this example, means building networks that support Indigenous youth in being both experts and knowledge users of sexual health information.

Changing Climate, Changing Health, Changing Stories

The Changing Climate, Changing Health, Changing Stories project provides a promising example of KT within a community-based research project. With funding from Health Canada’s First Nations and Inuit Health Branch, the Rigolet Inuit Community Government formed a trans-disciplinary team of Indigenous and non-Indigenous researchers to explore implications of climate change on physical, emotional, mental, and spiritual health [36, 37]. The project built from the rich oral tradition of Inuit knowledge systems by using digital storytelling and first-person narratives as methods for exploring and sharing local experiences of climate change. Through a series of week-long workshops, community participants shared and developed personal stories, while receiving training to produce these narratives as a digital short that weaved

their narrative with music, artwork, video clips, and photographs. KT occurred throughout the workshops as participants connected with themselves, their history, and the land through storytelling and dialogue. DVDs of the digital stories were made freely available to all participants and the community, and they were disseminated with permission of participants to policy makers and health professionals as well as posted online [36]. Perhaps most importantly, the project’s investment in technology, infrastructure, and community training led to the development of the “My Word: Storytelling and Digital Media Lab”, a community-run centre for digital media and research that continues to lead research in the community and the centre has expanded to offer a variety of research, media, and data-gathering services.

Indigenous Knowledge Network for Infant, Child, and Family Health

The Indigenous Knowledge Network for Infant, Child, and Family Health was a community partnered KT research project designed to support the gathering and application of Indigenous knowledge in 10 diverse First Nations, Métis, and urban Aboriginal communities. Ten frontline Aboriginal prenatal, infant, child, youth, and family health workers including midwives, health promotion program staff, health managers, and elders, were seconded to this project one day a week for four years. For the first two years they gathered oral histories from Indigenous elders and knowledge keepers in their communities of work. For the second two years they developed, implemented, and evaluated community-based knowledge application projects that drew on the Indigenous knowledge they had collected. The academic research team, based at the Well Living House Action Research Centre, supported program activities and facilitated network-wide meetings and interactions.

Evaluation of the network revealed very positive and transformative impacts for network participants, their clients, and the participant Aboriginal communities. Many of the knowledge application projects and relationships across the network and among network participants, community elders, and clients are ongoing. One of the keys to this project is that it actively builds on existing community resources and infrastructure. You can learn more about this project and the Well Living House Action Research Centre at <http://www.stmichaelshospital.com/crich/well-living-house/>.

Bridging Indigenous approaches to KT into health library science and practice

It is our hope that readers will now be full of ideas and questions regarding the application of Indigenous KT approaches in their health information work and practice. We would like to remind you that it is very likely that you are already actively engaged in KT activities, some of which are synergistic with Indigenous KT ideas and protocols. In fact, almost everything that a health librarian does could be considered KT, especially if one draws on the Indigenous notions of KT as a sharing of knowledge that is bidirectional, participatory, and social.

We have identified some specific strategies for implementing KT activities in Indigenous contexts in Table 1. More generally, it is our hope that readers will continue to think critically about their underlying assumptions regarding what is valid knowledge and what are valid knowledge-sharing strategies—and be open to different ideas. In some instances health librarians will be able to build on what they are already doing. For example with respect to reciprocity in relationships, many librarians will recognize that in their day-to-day work they are already engaged in mutually beneficial bi-directional knowledge exchange as they are always learning something new and understanding information needs before proceeding with assisting users. In other cases, implementing some of the suggestions may be more challenging. For example, a health librarian who has focused on supporting research, policy, and practice users in acquiring “best evidence” using standardized critical appraisal methods drawn from clinical epidemiology may need to expand their knowledge regarding best evidence for Indigenous contexts and build new skills in identifying, critically appraising, and sharing materials drawn from grey literature and multimedia.

Health librarians may also find themselves in a position where they can facilitate a bridging of the knowledge and knowledge system gaps between researchers working with Indigenous communities and Indigenous communities themselves. There is already a within-discipline distinction between research KT and consumer health information. Indigenous KT approaches require an entry into and immersion in the knowledge and knowledge system of the “consumer,” in this case the specific Indigenous individual or community in which the knowledge is to be applied. Also required is recognition that in passing through the doorway into an Indigenous knowledge system underlying assumptions from the outside may need to be revisited. For example, the assumption that health knowledge acquired through academic institutions will lead to more effective and higher quality health services for Indigenous peoples than knowledge derived from Indigenous peoples themselves or the assumption that research KT processes are completely distinct from the provision of consumer health information. For within an Indigenous context what might be most important with respect to research KT is helping the researcher understand the pre-existing health knowledge theories and practices of the Indigenous individual or community (i.e., the consumer).

For those who have already acquired knowledge and experiences regarding Indigenous approaches to knowledge and knowledge sharing, please share with others who have not had these opportunities through dialogue, training, and experiences. We would encourage each of you to build allegiances across Indigenous–non-Indigenous and community–academic divides. Critical self-reflection and communication regarding your own identity and intentions will support the building of allied relationships. Finally, when in doubt, ask. Find an Indigenous or allied colleague who has identified themselves as being available as a resource person and who you think may have the answer to your question or at least be able to direct you to the appropriate resource. Keep in mind the principles of mutual respect and reciprocity in your approach.

We have done our best in this article to share knowledge and resources to support readers interested in understanding and applying Indigenous approaches to KT. We recognize that some of the concepts, critical questions, strategies, and examples may be challenging for readers. However, we believe that much of the content is relevant not only to KT but also to other health and social science research, service, and policy work in Indigenous contexts. “New” ideas and strategies, such as KT, are constantly emerging in health and health information sciences. For example current CIHR strategies include terms such as “implementation science” and “evidence informed health-care renewal”. One commonality that will likely be shared by many of these future health science research and (or) practice directions is that they will exclude or marginalize Indigenous systems of knowledge and practice. A few, however, will realize the gains in both process and outcomes that can be made by keeping Indigenous ways of knowing and doing in mind—not only for Indigenous communities but for all peoples.

References

1. Government of Canada. Canadian Institutes of Health Research Act. S.C 2000, c. 6. Assented April 13, 2000. [Cited 21 January 2014]. Available from: <http://laws-lois.justice.gc.ca/eng/acts/C-18.1/>.
2. Canadian Institutes of Health Research. Knowledge translation strategy 2004–2009: Innovation in Action. Canadian Institutes of Health Research. [Internet]. Ottawa: Canadian Institutes of Health Research; 2004 [Cited 18 January 2014]. Available from: <http://www.cihr-irsc.gc.ca/e/26574.html>.
3. Henderson J. Knowledge translation for Canadian health libraries: Finding our place between knowledge and its user. Paper presented at: Canadian Health Libraries Association Conference; 2011 May 29; Calgary. [Cited 18 January 2014]. Available from: <http://www.chla-absc.ca/2011/node/161>.
4. LaRocca R, Yost J, Dobbins M, Ciliska D, Butt M. The effectiveness of knowledge translation strategies used in public health: a systematic review. *BMC Public Health*. 2012;12:751.doi: 10.1186/1471-2458-12-751.
5. Wien F. A dance to create meaning together: perspectives on the ACADRE network on knowledge translation. [Internet]. AHRNet/NEAHR Resources; 2006 March 1. [Cited 21 January 2014] Available from: http://ahrnets.ca/files/2010/05/A_Dance_to_Create_Meaning_March2006.pdf.
6. Ranford J, Warry W. Knowledge transfer/knowledge translation project summary report. [Internet]. AHRNet/NEAHR Resources; 2006 [Cited 21 January 2014]. Available from: <http://ahrnets.ca/files/2010/05/IHRDP-Knowledge-Translation-Summary-Report-IHRDP.pdf>.
7. Rikhy S, Jack M, Campbell L, Tough S. Knowledge exchange as a vehicle to improve the health of Aboriginal communities. *Pimatisiwin*. 2008;5(2):107–124.
8. Smylie J, Kaplan-Myrth N, McShane K. Indigenous knowledge translation: baseline findings in a qualitative study of the pathways of health knowledge in three indigenous communities in Canada. *Health Promot.Pract.* 2009;10(3):436–46. doi: 10.1177/1524839907307993.

9. Tuhiwai Smith L. *Decolonizing methodologies: research and indigenous peoples*. London: Zed Books; 1999.
10. Estey E, Smylie J, Maccauly A. Aboriginal knowledge translation: understanding and respecting the distinct needs of aboriginal communities in research. [Internet]. Canadian Institute for Health Research; 2009. [Cited 17 January 2014] Available from: <http://www.cihr-irsc.gc.ca/e/41392.html>.
11. Guba E, Lincoln, Y. Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS, editors, *Handbook of qualitative research*. Thousand Oaks, CA: Sage; 1994. 105–117.
12. Ermine, W. Aboriginal epistemology. In: Battiste M, Barman J, editors, *First Nations education in Canada: The circle unfolds*. Vancouver: University of British Columbia Press; 1995. 101–112.
13. Little Bear L. Jagged worldviews colliding. In: Battiste M, editor, *Reclaiming Indigenous voice and vision*. Vancouver: University of British Columbia Press; 2000.
14. Brant Castellano M. Updating Aboriginal traditions of knowledge. In: Sefa Dei GJ, Hall BL, Rosenberg D, editors, *Indigenous knowledges in global contexts*. Toronto: University of Toronto Press; 2000. 21–36.
15. Kaplan-Myrth N, Smylie, J. Sharing what we know about living a good life. Summit report from the indigenous knowledge translation summit; 2006 March 2–5; Regina, SK. [Cited 18 January 2014]. Available from: http://iphrc.ca/assets/Documents/Final_Summit_Report_Sept_30.pdf.
16. Smylie J. Knowledge translation and indigenous communities: a decolonizing perspective. In: Banister E, Leadbeater B, Marshall A, editors. *Knowledge translation in context*. Toronto: University of Toronto Press; 2011.
17. Cajete G. Indigenous knowledge: the Pueblo metaphor of indigenous education. In: M Battise, editor, *Reclaiming indigenous voice and wisdom*. Vancouver: UBC Press; 2000. 181–208.
18. Estey E, Kmetz A, Reading, J. Knowledge translation in the context of Aboriginal Health. *CJNR*. 2008;40(2):24–49.
19. Little Bear L. Jagged worldviews colliding. In: Battiste M, editor, *Reclaiming Indigenous voice and vision*. Vancouver: University of British Columbia Press; 2000.
20. Nursing Council of New Zealand. *Guidelines for cultural safety, the treaty of Waitangi, and Maori health in nursing and midwifery education and practice*. Wellington: Nursing Council of New Zealand; 2002.
21. National Aboriginal Health Organization. Fact sheet; cultural safety. [Internet]. National Aboriginal Health Organization; 2006 January 31 [Cited 18 January 2014] Available from: <http://www.naho.ca/documents/naho/english/Culturalsafety-factsheet.pdf>.
22. Adelson N. The embodiment of inequity: health disparities in Aboriginal Canada. *Can J Pub Health*. 2005;96(S2):S46–S61.
23. Firestone M. *Our health counts: Unmasking health and social disparities among urban Aboriginal people in Ontario*. Toronto: University of Toronto; 2013.
24. Reading J. The crisis of chronic disease among Aboriginal people: A challenge for public health, population health and social policy. [Internet]. Victoria: University of Victoria Centre for Aboriginal Health Research; 2009 [Cited 21 January 2014]. Available from: http://cahr.uvic.ca/docs/ChronicDisease_Final.pdf.
25. Rootman I, Gordon-El-Bihbety D. A vision for a health literate Canada. [Internet]. Ottawa: Canadian Public Health Association; 2008. [Cited 21 January 2014]. Available from: http://www.cpha.ca/uploads/portals/h-l/report_e.pdf.
26. Canadian Council on Learning. The state of Aboriginal learning in Canada: a holistic approach to measuring success. [Internet]. Ottawa: Canadian Council on Learning; 2009. [Cited 21 January 2014]. Available from: http://www.ccl-cca.ca/pdfs/StateAboriginalLearning/SAL-FINALReport_EN.PDF.
27. George NP. The rainbow/holistic approach to aboriginal literacy. *Canadian Journal of Native Education*. 2003;27(1): 29–40.
28. Battiste M, Youngblood Henderson JS. *Protecting indigenous knowledge and heritage*. Saskatoon: Purich Press; 2000.
29. First Nations Centre. OCAP: Ownership, control, access and possession. [Internet]. Sanctioned by the First Nations Information Governance Committee, Assembly of First Nations. Ottawa: National Aboriginal Health Organization; 2007 [Cited 31 January 2014]. Available from: <http://cahr.uvic.ca/nearbc/documents/2009/FNC-OCAP.pdf>
30. Ermine W. Cree Religious Ethos. [Internet]. University of Regina and Canadian Plains Research Centre; 2007 [Cited 21 January 2014]. Available from: http://esask.uregina.ca/entry/cree_religious_ethos.html.
31. Kirkness V, Barnhardt R. First Nations and higher education: the four Rs—respect, relevance, reciprocity, responsibility. *Journal of American Indian Education*. 1991;30(3):1–15.
32. McCaskill D, FitzMaurice K, Cidro J. *Toronto Aboriginal Research Project (TARP) Final Report*. Toronto: Toronto Aboriginal Support Services Council; 2011.
33. Smylie J, Firestone M, Cochran L, Prince C, Maracle S, Moreley M, Mayo S, Spiller T, MacPherson B. Our health counts: community report. [Internet]. Toronto: Our Health Counts; 2011 [Cited 18 January 2014]. Available from: <http://www.ourhealthcounts.ca/images/PDF/OHC-Report-Hamilton-ON.pdf>.
34. Welch V, Petticrew M, O'Neill J, et al. Health Equity: Evidence synthesis and knowledge translation methods. *Syst Rev*. 2013;2:43.doi: 10.1186/2046-4053-2-43.
35. Native Youth Sexual Health Network. What we do. [Internet]. Native Youth Sexual Health Network website; 2014 [Cited January 2014]. Available from: <http://www.nativeyouthsexualhealth.com/whatwedo.html>.
36. Cunsolo Willox A, Harper S, Edge V. My Word: Storytelling and Digital Media Lab, Rigolet Inuit Community Government. Storytelling in a digital age: digital storytelling as an emerging narrative method for preserving and promoting indigenous oral wisdom. *Qualitative Research*. 2013;13(2): 127–147. doi: 10.1177/1468794112446105.
37. Harper SL, Edge VL, Cunsolo Willox A, Rigolet Inuit Community Government. “Changing climate, changing health, changing stories” profile: using an EcoHealth approach to explore impacts of climate change on inuit health. *Ecohealth*. 2012;9(1):89–101. doi: 10.1007/s10393-012-0762-x.

Non-insured Health Benefits for First Nations and Inuit People: an Overview for Information Providers

Jessie Loyer and Marija Small Legs

The Non-insured Health Benefits (NIHB) program provides First Nations and Inuit people in Canada with coverage for a limited range of medically necessary goods and services. These can include prescription drugs, dental care, vision care, medical supplies and equipment, short-term crisis counselling, and medical transportation [1]. This article provides health librarians and other providers of consumer health information with some background on the program, differing perspectives on the legal and treaty requirements for service provision, the health literacy implications, and the role of a Treaty 7 NIHB Navigator in service delivery.

Background and perspectives on the provision of NIHB

Health care has been perceived in vastly different ways by government and First Nations people. Government support of medical services for First Nations, Inuit, and Métis people has a long history and various departments have been responsible over the years. The Medical Services Branch of Health Canada (MSB) was created in 1962 when various field services were merged with the Indian Health and Northern Health Services. MSB was renamed the First Nations and Inuit Health Branch in 2000 and now administers NIHB [2].

The federal government claims the NIHB program supports registered First Nations and recognized Inuit in reaching an overall health status comparable to other Canadians. Though their health status is not equal and comparable, First Nations and Inuit people continuously work to ensure their health needs are met and are equal to other Canadians, and they assert that health benefits are an inherent Aboriginal and Treaty right and are constitutionally protected [3].

In 1974, the federal government's position was written in a policy that stated there were no statutory or treaty obligations for providing health services to Indians, though the federal government would provide services and give financial assistance when medically necessary [2]. They had also previously noted in 1957 that under Treaty Six medical care was an obligation, but medical services for all Indians were provided on humanitarian rather than on legal grounds [4]. This difference in perspective creates barriers

and jurisdictional issues around access to health care for First Nations and Inuit people.

Treaty Six is the only treaty that specifically mentions health care in its text, which includes the clause for a medicine chest to be held at the Indian agent's home and offers emergency help, for example during epidemics. These clauses have been interpreted in various ways, particularly around the extent of care [4]. However, the Supreme Court affirmed that the terms of treaties are not limited to the text in the treaty, but rather include the actual agreements between the parties [3]. Historical documents show that several other treaty negotiations included discussions about the provision of medical services, but those discussions did not appear in the final text of the treaty [4].

In addition to these specific clauses in Treaty Six, there are other supporting arguments around treaty rights and health care. Historical events support the First Nations assertion that medical care was tied to treaty rights. The connection between treaty and health care was solidly entrenched, with doctors frequently in attendance when treaty annuities were paid out, so much so that people at York Factory in Treaty Five spoke out in anger when no doctor accompanied the annuity treaty payments of \$5 in 1915 [4].

From a First Nations historical perspective, disagreements over jurisdiction and responsibility for the delivery of medical services influence current obstacles to access for First Nations and Inuit patients. These obstacles can include funding for the NIHB program, effective communication, limited transportation, and in many cases, limited access to provincial health services and programs if clients reside on reserve. When the Assembly of First Nations (AFN) assessed the NIHB program in 2005, they found that increases in funding levels were only limited to an estimated population growth rate. Health needs and cost drivers were not considered as part of the funding equation [3]. As well, cutbacks in the 1990s confused clients as benefits were delisted, eligibility and access changed, and generic drugs were encouraged; these changes continue today. Before certain medications could be accessed at a

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pharmacy, Health Canada demanded that doctors and other health care providers submit their services for prior approval and predetermination for many drugs and for dental services, which complicated the process [3]. These processes are still complicated today through predetermination, which is a process of prior approval where health care providers must submit cases to Health Canada for review; prior approval is time consuming and is required to access all vision care, transportation, and counselling, most dental, medical supplies and equipment benefits, and for some drug benefits [1].

Unlike private health care plans, NIHB has many limitations and barriers to accessing services; funding to these services decreases yearly, which limits coverage. The NIHB processes currently in place are time consuming, financially draining, and often the ultimate result will be a denial. Providers are often unwilling to work with the burdensome NIHB process. Health Canada considers itself the Payer of Last Resort, and state that "where a benefit is covered under another plan" they promote that plan instead of providing health care coverage [1]. NIHB Navigators help to empower First Nations and Inuit clients to ensure that they can advocate to enhance their health care and to ensure their needs are met and that the care delivered is equal to that of other Canadians.

Access to NIHB is also limited by identity categorization. NIHB is one of the only federal programs for First Nations that extends beyond reserve borders. Any registered Indian and recognized Inuit person can access these benefits, regardless of where they live [6]. However, NIHB does not cover the health care of those not recognized by the Canadian federal government such as non-status Indians, non-recognized Inuit, or Métis people who do not have access to the same benefits thanks to these "historically produced categorizations of indigenous people" [6].

Health literacy implications

Confusion among clients over access and coverage has health literacy implications. In Canada, health literacy is defined as "the ability to access, understand, evaluate, and communicate information as a way to promote, maintain, and improve health in a variety of settings across the life-course" [7]. Health librarians working with First Nations and Inuit people should keep in mind that these clients may not be aware of all services available to them under the NIHB program.

For patients to access required medical services, they first need to be informed about the changes to their care. Information on changes to the NIHB program benefits is often not communicated in a clear and timely fashion, leaving First Nation and Inuit members uninformed until they access the service or care. Information about NIHB is often confusing, particularly for elders who are frequent users of medication, dental care, and ophthalmology services [6]. When asked about communication around health care by the National Aboriginal Health Organization, a sample of First Nations respondents felt that health information was not readily available, that it was difficult to access, and that there were large areas of health care services not represented well. Although this survey does not represent all First Nations in Canada, of those

surveyed nearly 50% did not know how easy it was to access midwives, 20% did not know about the accessibility of mental health services, and 18% did not know about access to pediatricians, addictions workers, and social workers [8].

When surveyed about what would improve Aboriginal health, 85% of respondents cited the need for more information on health-related topics in their communities [8]. In another survey when asked about NIHB and Health Canada, communication strategies such as seminars, community education sessions, and regular info bulletins were identified as helpful strategies to navigate the complicated and time-consuming processes [3]. People overwhelmingly agreed that clear, culturally relevant information would not only help them navigate their health care, including NIHB, but also improve their overall health.

The role of NIHB Navigators

Because health benefits vary according to region, some regions may have more provincial and territorial support than others, and general resources describing the NIHB program may not fully answer clients' specific questions about their regional coverage; experts at the regional level are crucial to navigate issues, barriers, and obstacles. This expertise takes the form of NIHB Navigators such as Marija Small Legs, one of this article's authors, who works with First Nations and Inuit people in the Treaty 7 territory and Alberta region. NIHB Navigators support and provide assistance to eligible First Nations and Inuit clients in accessing the NIHB Program. The role of a Navigator is to support First Nation and Inuit communities in gaining an increased understanding of existing health services, jurisdictional issues, and the limitations of the NIHB program. The Navigator works to exchange, gather, and collate information on health access issues and denials of services. This data can be used to identify areas where health services can be improved for their clients. The NIHB Navigator can advocate on the behalf of their clients through the appeal process when a benefit has been denied and liaises with regional Health Canada staff to support their communities through this process.

In Alberta Treaty 6, Treaty 7, and Treaty 8 all have their own Navigators, but these Navigators work together to ensure they meet the needs of all Treaty First Nation and Inuit members regardless of jurisdiction. This enables the Navigator to strengthen relationships with health care providers, professionals such as pharmacists, and communities and to create and enhance partnerships. They also work to inform, educate, and provide information and support to those having difficulty accessing and navigating the policy, procedures, and the numerous administrative requirements of the NIHB program for accessing NIHB services or when dealing with NIHB providers.

First Nations and Inuit peoples face many challenges to their healthcare; some examples include transportation, access to prescription medicines that may be removed from the Drug Benefit List (DBL), and preauthorization criteria for some services. NIHB Navigators can assist patients with these obstacles and connect them to the services they require if they exist and no jurisdictional issues apply.

Many health services are not located on First Nation reserves. Individuals may have to commute great distances

from their communities to obtain health care and services. Clients must coordinate with medical transportation to attend appointments outside of their community within specified timeframes; this can be quite burdensome and stressful for those who are ill and elderly and who may need to be transported in a van with other patients, regardless of the time their appointments are scheduled. If medical transportation is required after work hours many clients are left stranded without any way to return to their communities.

Prescription medications can often be unlisted or delisted from NIHB's DBL. A medication may be prescribed, but may not be available for access under the NIHB pharmacy plan. For example, a client may go to the pharmacy and be informed that the drug is not listed on the DBL, despite the fact that their medication may be essential for their care. Limited use prescribed medications may be considered for NIHB program coverage under special circumstances with prior approval. First Nations and Inuit clients must request that their pharmacist resubmit the claim if not approved and have the prior approval request reviewed by the NIHB Drug Exception Centre (DEC). Navigators encourage and advise First Nation members to inform pharmacies to contact DEC to determine if an exception can be made and have Health Canada provide the prescribed medication. When a request is denied, the NIHB Navigator may assist First Nations and Inuit clients to appeal unfavourable decisions if they so choose.

NIHB Navigators are excellent resources for building capacity around health literacy. Navigators also link First Nations and Inuit patients to the programs and services they can access and help them navigate a complicated system. To better serve their First Nations and Inuit users who may have difficulty accessing NIHB, libraries should make connections with the NIHB Navigators in their region.

Further resources

Complete information on the NIHB program, including regional offices, can be found on Health Canada's web

site at: <http://www.hc-sc.gc.ca/fniah-spnia/nihb-ssna/index-eng.php>. Information about regional navigators can be found through Health Canada regional offices, First Nation regional offices, or AFN Caucus members.

References

1. Health Canada & Assembly of First Nations. Your health benefits: a guide for First Nations to access non-insured health benefits. *Alberta Region*. Health Canada; 2013. 41 pp.
2. Health Canada. *History of providing health services to First Nations people and Inuit [Internet]*. Ottawa: Health Canada; 2010. [cited 24 January 2014]. Available from: <http://www.hc-sc.gc.ca/ahc-asc/branch-dirgen/fnihb-dgspni/services-eng.php>.
3. Assembly of First Nations. *First Nations action plan for non-insured health benefits*. Ottawa, ON: Assembly of First Nations; 2005. 32 pp.
4. Waldrum JB, Herring DA, Young TK. editors, editors. *Aboriginal health in Canada: historical, cultural, and epidemiological perspectives*. 2nd ed. Toronto: University of Toronto Press; 2007. 367 pp.
5. Assembly of First Nations. *First Nations action plan for non-insured health benefits*. Ottawa: Assembly of First Nations; 2005. 32 pp.
6. deLeeuw S, Greenwood M. Beyond borders and boundaries: Addressing Indigenous health inequities in Canada through theories of social determinants of health and intersectionality. In Hankivsky O, editor, editor. *Health inequalities in Canada: Intersectional frameworks and practices*. Vancouver: UBC Press; 2011. 412 pp.
7. Rootman I, Gordon-El-Bihety D. *A vision for a health literate Canada: report of the Expert Panel on Health Literacy*. Ottawa: Canadian Public Health Agency; 2008. 48 pp.
8. First Nations Centre, National Aboriginal Health Organization. *What First Nations think about their health and health care: the National Aboriginal Health Organizations' public opinion poll on First Nations health and health care in Canada*. Ottawa, ON: National Aboriginal Health Organization; 2004.

FEATURE / MANCHETTE

The Arctic Council: a Brief History, its Partnership with Indigenous Groups of the Arctic, and its Role in Uncovering and Addressing Health Issues in the Far North

Kathleen Murray

Abstract: The Arctic Council is an international forum, a venue in which the eight Arctic states can cooperate "...on common Arctic issues, in particular issues of sustainable development and environmental protection." Canada played a major role in the creation of the Council in 1996 and is the Chair of the Council for 2013–2015. The Arctic Council's current focus is on the responsible development of Arctic resources, development of safe Arctic shipping, and supporting sustainable circumpolar communities. Indigenous peoples' organizations from the eight states that participate in the Arctic Council are formally recognized as Permanent Participants and have helped shape the development of the Arctic Council. They also initiate and participate in various projects. Since 2009, the Arctic Council has increasingly focused on health- and wellness-related issues, and its Working Groups and associated project groups have produced data, reports, and documents that are of interest to librarians, clinicians, policy makers, and others concerned with Arctic health. This paper briefly addresses the history, structure, focus, health initiatives, and publications of the Arctic Council. Because of the complex structure and history of the Arctic Council, its publications can be difficult to find, and this report provides helpful tips for obtaining relevant information. The report concludes with some interesting developments in the growing interest by non-Arctic countries wanting to participate in the Arctic Council.

Background

More than four million people who live in the Arctic are citizens of the eight states that participate in the Arctic Council. The Arctic is water surrounded by land that is home to the Inuit, the Aleuts, the Athabaskan, the Saami, and the 41 Indigenous groups living in the Russian Federation. In contrast, the Antarctic is land surrounded by water and is the temporary home for a few thousand scientists and researchers in the summer and just a few hundred in the winter. There is a growing awareness of the impacts of climate change on both poles. These changes directly impact the people who live in the North with loss of access to food sources, land erosion causing destruction of homes, and organic pollutants that impact food and human health. This article describes the history, structure, function, and health initiatives of the Arctic Council, a group whose mission includes the well-being of Indigenous peoples living in the North.

History

Concerns about environmental pollution impacting the health of Indigenous populations living in the Arctic

surfaced at the end of the Cold War. Finland led the creation of the Arctic Environmental Protection Strategy (AEPS) in the 1980s in response to persistent organic pollutants that were mainly created by non-Arctic countries but ended up in the food supply of northern peoples. This group focused almost entirely on environmental issues and the enhancement of cooperation amongst Arctic institutions. The AEPS had eight nation-state members, including Canada, and they established four working groups monitored by the states, observers, and Indigenous groups. The following working groups still function as part of the Arctic Council:

- The Arctic Monitoring and Assessment Program (AMAP) monitors and assesses pollutants in the Arctic. They produce assessment reports and recommend responses.
- The Conservation of Arctic Flora and Fauna (CAFF) exchanges information on how Indigenous peoples use and interact with Arctic species.
- The Emergency Prevention, Preparedness, and Response group provides a framework for cooperation in response to environmental emergencies. It created a system of early notification in case of an event.

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- The Protection of the Arctic Marine Environment (PAME) group conducts activities related to the protection and sustainable use of the arctic marine environment.

Canada, among other nation-state members, wanted to see the AEPS mandate expanded to include economic development for the Arctic. Canada led the effort to merge the existing AEPS working groups into a new organization that would address the broader issue of sustainable development. The United States had issues with some of the structure proposed by Canada but agreed to participate in the newly formed Arctic Council after it was established as a forum without “legal personality,” meaning that it is not an “international organization” in terms of international laws [1]. The *Declaration on the Establishment of the Arctic Council* was signed in Ottawa on 19 September 1996 (the “Ottawa Declaration”).

Structure

The formal structure of the Arctic Council is outlined in the Ottawa Declaration. Understanding the infrastructure of this unique organization will hopefully clarify how their work is done and why finding their publications can be a bit of a detective hunt. There are three categories of participants: States, Permanent Participants, and Observers. Decisions are by consensus of the eight Arctic States in consultation with the Permanent Participants.

The eight states whose ministers meet every two years include Canada, Denmark (Greenland and the Faroe Islands), Finland, Iceland, Norway, Russia, Sweden, and the United States. Each state appoints a Senior Arctic Official (SAO). The SAOs meet every six months and direct the work of the Council on a day-to-day basis. In addition to the eight members, there is a chair of the SAO from the country currently chairing the Council. The current SAO Chair is Patrick Borbey from Canada.

Indigenous peoples living in these eight countries are represented as Permanent Participants. The Ottawa Declaration recognized the role of traditional knowledge of Indigenous peoples in the “collective understanding of the circumpolar Arctic” and committed to the well-being of the inhabitants of the region. The three Indigenous organizations involved with AEPS efforts, the Inuit Circumpolar Conference, the Saami Council, and the Russian Association of Indigenous Peoples of the North (RAIPON), are mentioned as providing valuable support in the development of the Arctic Council. Currently, there are six Permanent Participants: the Inuit Circumpolar Conference, the Saami Council, the RAIPON, the Arctic Athabaskan Council, the Gwich’in Council International, and the Aleut International Association. One extremely positive outcome of Permanent Participants having a seat at the table is the focus this brings to the needs and views of Indigenous Arctic residents, particularly issues concerning sustainable development. Permanent Participants can suggest projects and their members participate in the working groups.

An Indigenous Peoples’ Secretariat was established in 1994 and this office became part of the Arctic Council

framework. Their work is to relay documents and reports between the Permanent Participants and the Council and its Working Groups and they provide coordination for the Indigenous peoples’ organizations to meet with each other and participate in the Arctic Council Working Groups.

Observer status is open to non-Arctic states and others. The expectation is that these states and organizations will contribute their knowledge and expertise in multiple ways to the work of the Arctic Council. The current list of observers is on the Arctic Council website (<http://www.arctic-council.org/index.php/en/about-us/arctic-council/observers>).

The permanent Arctic Council Secretariat opened its doors on 3 June 2013 in Tromsø, Norway. Although having a single administrative base will help smooth the transition between chairmanships that rotate every two years, another reason for its establishment is the need to communicate the findings of the working groups to citizens of the Arctic and to other countries. The primary functions for this office are communication, administration, and translation.

The Arctic Council’s working groups are staffed with scientists, researchers, and other experts concerned about issues of immense import to people living in the North. Librarians would be welcomed as contributors to working group activities. I became aware of the Arctic Council and its work when presenting the development of the Arctic Health website to the Council in 2002. This website, managed jointly by the US National Library of Medicine and the Alaska Medical Library at the University of Alaska Anchorage, includes a growing section dedicated to data on the health of Indigenous peoples of the circumpolar Arctic as well as an extensive publications database. I have also supported some of the Council’s research efforts by conducting literature searches and hosting the Arctic Human Health Initiative website, described later in this article.

Focus

The role of the Arctic Council is described by the Ottawa Declaration [2]. Each country, during its chairmanship, develops its own set of priorities for its two-year term. For 2013–2015, during Canada’s term, the goals include establishing guidelines for sustainable tourism and cruise ship operations, developing a mandatory polar code (dealing with shipping) for the Arctic Ocean, developing recommendations for incorporating traditional and local knowledge into the work of the Arctic Council, addressing short-lived climate pollutants, promoting mental wellness, and supporting the conservation of migratory birds, a food staple for northern communities. Notable in May 2013, the Arctic states signed an “Agreement on Cooperation on Marine Oil Pollution Preparedness and Response in the Arctic.”

Working groups develop projects and conduct research. Ministers, Permanent Participants, and the members of the working groups develop the list of projects; however, Ministers authorize projects.

Human health initiatives are a more recent addition to the work of the Council. Human health in the north is impacted by many factors. It is simplistic to say that only

two of the working group outcomes should be considered when thinking about human health issues. However, the Sustainable Development Working Group (SDWG) and the Arctic Contaminants Action Program (ACAP) are where many of the Arctic Council's health initiatives live. The SDWG was created at the first Ministerial meeting in 1998. After the SDWG was formed, Canada presented a project focusing on the health and education of children and youth, whereas the United States proposed projects to improve telemedicine services to remote areas in the Arctic and to improve Arctic sanitation systems. The Saami Council presented two proposals related to fisheries management issues. The ACAP was formally given working group status in October 2006.

Health issues: projects and publications

The addition of specific human health initiatives really expanded during the International Polar Year (2007–2008) as part of the Arctic Human Health Initiative (AHHI), an Arctic Council International Polar Year coordinating project. Abstracts, journal articles, and updates for each of the projects can be found on the AHHI website (<http://www.consortiumlibrary.org/aml/ahhi/proposals/index.htm>). The goal of the AHHI was to increase human health research, education, outreach, and communications. The Tromsø declaration of 29 April 2009 acknowledged “the increased focus on human health in the work of the Arctic Council, including the establishment of the new Arctic Human Health Experts Group under the Sustainable Development program” (<http://www.arctic-council.org/index.php/en/document-archive/category/5-declarations?download=38:tromso-declaration>). Special supplement number six of the *International Journal of Circumpolar Health* in 2010 describes the 28 projects that have continued under the Arctic Human Health Expert Group (AHHEG) (http://www.circumpolarhealthjournal.net/public/journals/32/chs/CHS_2010_6.pdf).

The work plan for the AHHEG developed for 2009–2010 included a list of knowledge gaps and tasks assigned to members of the group: climate change and infections, Saami health and health care, education of health staff, maternal and child health, suicide prevention seminar, documentation of inequalities, and dietary recommendations along with the known health issues presented in Table 1.

Since the Tromsø declaration, a number of projects promoting health and well-being for the peoples of the Arctic have been initiated:

- **Comparative Review of Circumpolar Health Systems Report (AHHEG–Canada–Greenland).** Phase one of this multi-year project is to assemble national and regional profiles of the different health systems in Arctic countries.
- **International Circumpolar Surveillance (ICS) (USA).** The ICS established an infectious disease surveillance network of hospital and public health laboratories and authorities throughout Arctic regions to monitor emerging and infectious disease problems. The network collects and shares data between Arctic countries

Table 1. Known health issues for Arctic peoples

Issue	Cause
Mental health and suicide	<ul style="list-style-type: none"> • marginalization • depression • youth suicides • substance abuse
Diet and nutrition	<ul style="list-style-type: none"> • food security • obesity • safe water • fluoridation • cardiovascular disease and diabetes
Health care	<ul style="list-style-type: none"> • health care to Indigenous populations • culturally appropriate health care to the elderly • rapid turn-over of staff • cultural education of health staff
Inequalities in health	<ul style="list-style-type: none"> • circumpolar inequalities • nonexistent documentation for inequalities
Other	<ul style="list-style-type: none"> • no monitoring of the health effects of climate change • infectious diseases (STD, tuberculosis) • ICS requires expansion • violence • child and youth health and wellbeing not monitored • tobacco • unintentional injuries • more money allocated for health resources • cancer

and assists in creating prevention and control strategies. It is an activity of the AHHEG.

- **Arctic Human Health Minister's Meeting.** The meeting was held in Nuuk, Greenland, in February 2011. At this meeting the Ministers recognized the “continued health challenges and noted the need to improve physical and mental health and well-being and empowerment of Indigenous peoples and residents of Arctic communities.” (<http://www.arctic-council.org/index.php/en/environment-and-people/arctic-peoples/health-well-being/166-health>)
- **Hope and Resilience in Suicide Prevention Seminar (Greenland–Denmark–Canada).** This seminar was held in Nuuk, Greenland, on 7–8 November 2009. “This first activity under the auspices of the SDWG AHHEG brought together social workers and health practitioners, researchers, policy makers, and politicians to exchange best practices aimed at reducing the number of suicides in the Arctic countries, particularly among youth. The seminar participants produced recommendations for future actions, a DVD including a video produced by the youth participants, and a seminar report that was translated into Russian with funding provided by Canada.” (<http://www.arctic-council.org/index.php/en/environment-and-people/arctic-peoples/health-well-being/166-health>)
- **Circumpolar Health Observatory (Canada–Denmark–Greenland).** This is an international collaborative health information system housed in Yellowknife, Canada. This project monitors trends and patterns

in health status, health determinants, and health care. The collaborative maintains a searchable and interactive databank of relevant circumpolar human health publications and statistical reports. The website currently contains circumpolar health data for 2000–2004. Data updates are underway for 2005–2009.

- **Circumpolar Nutrition Guide (Canada–Denmark–Greenland).** This is an AHHEG project managed by the Greenland Institute for Health Research. Over two years, this group assembled existing information on nutritional guidelines in circumpolar countries. The final report was peer reviewed and published as a Circumpolar Health Supplement in the *International Journal for Circumpolar Health* in 2011 (http://www.circumpolarhealthjournal.net/public/journals/32/chs/CHS_2011_8.pdf).

Where is that document?

Documents are created at the different levels of the Arctic Council: ministerial declarations, working group created assessments and reports, expert group documents, etc. These documents are found in a number of locations on the Council's website and even in remote locations such as the AHHI website. The Arctic Council's home page top navigation bar has a link to the "Document Archive," which includes founding documents and selected other publications grouped by headings such as declarations, Arctic strategies, ministerial meetings, and events. However, many reports and assessments are found within each working group's own website, which are linked from the main Arctic Council website.

AMAP's website has sections for projects, data, and documents. Their documents are grouped into folders labeled assessment reports, technical reports, videos, etc. (<http://www.amap.no/documents/18/documents/2>). CAFF's website also groups its output by categories such as monitoring (219 documents), assessment (294 documents), or strategies (40 documents) (<http://www.caff.is/publications>.) PAME's website lists documents in a document library but also under the latest publications link (<http://www.pame.is/>).

The SDWG published a number of reports with a health focus during 2009–2011. The full text for each of these documents can be found on the SDWG website (<http://www.sdwg.org/content.php?doc=23>). A sampling of these documents includes the *International Circumpolar Surveillance*, the *Circumpolar Health Systems Review*, the report from the Arctic Human Health Initiative, a summary report from the *Hope and Resilience in Suicide Prevention Seminar*, the *Circumpolar Nutrition Guide*, and the *Survey of Living Conditions in the Arctic (SLiCA)*.

Given the scattered nature of where documents are housed, here are the suggested steps to track down a specific publication:

- Use the search box on the document archive page for the Arctic Council (<http://www.arctic-council.org/index.php/en/document-archive>). Enter a very

simple search. Scroll through the documents and look closely at the filenames, as the "title" may not be obvious. Can't find it here?

- Check the Working Group website. If you believe a working group published a report and you can't find it, use the list of contacts on each working group website. Still no luck?
- If you know when it was published, check the Senior Arctic Official meeting documents for that year (<http://www.arctic-council.org/index.php/en/events/meetings-overview/all-meetings>).
- If you don't know when the document might have been created, but you have a good idea of the content, contact the Secretariat. This office has been extremely responsive to my inquiries. They want you to find the information you need and will dig through their files and contacts to help locate their publications (<http://www.arctic-council.org/index.php/en/contact>).

The future

Natural resources abound in the Arctic. As a result, a growing number of non-Arctic countries are asking for Observer status. As of the end of 2013, 12 non-Arctic countries have been admitted as Observers to the Arctic Council: France, Germany, The Netherlands, Poland, Spain, United Kingdom, People's Republic of China, Italian Republic, State of Japan, Republic of Korea, Republic of Singapore, and the Republic of India. China, Japan, South Korea, India, Singapore, and Italy all joined in 2013. The European Union's request was put on hold pending further discussion after it launched its own Arctic Study in 2008 without consulting the Arctic Council and banned the import of seal products [1].

Why this interest? The Arctic is facing turbulent times. The Arctic Council has an obvious role. As Young [3] (p. 82) states "The council is not endowed with authority to make formal decisions about public issues on its own. What it does best is to identify emerging issues in a timely manner, provide authoritative assessments regarding important features of these issues, draw them to the attention of non-Arctic specialists, move priority concerns toward the head of the queue on relevant policy agendas, and offer a venue for efforts to address specific concerns."

As medical librarians, we are well served by following the issues addressed by the Arctic Council. Their concerns about food security, infectious diseases, and other health concerns for all who live in the far north, lead to the creation of research and publications that should be shared with our researchers and clinicians. We could also assist these efforts by working within the different working groups providing our expertise in database development, website usability studies, and literature searches. I have reached out to different projects and my offers of help have always been gratefully received.

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References

1. Chaffin J. Canada slows EU entry to Arctic Council. FT.com 29 Apr. 2009.
2. Ottawa Declaration 1996. [Internet]. Arctic Council; 2013 [cited 12 Dec 2013]. Available from: <http://www.arctic-council.org/index.php/en/document-archive/category/5-declarations?download=13:ottawa-declaration>.
3. Young OR. Arctic tipping points: governance in turbulent times. *Ambio*. 2012;41(1):75–84. doi: 10.1007/s13280-011-0227-4.

Other Resources

Bloom ET. Establishment of the Arctic Council. *Am J Int Law*. 1999;93(3):712–22. doi: 10.2307/2555272.

Chaffin J. Canada slows EU entry to Arctic Council. FT.com 2009 Apr. 29.

Charron A. Canada and the Arctic Council. *Int'l J*. 2012; 67(3):765–83.

Crook JR. United States and other arctic nations conclude first international agreement under Arctic Council auspices. *Am J Int Law*. 2011;sec. 105:580.

Eicken H, Forbes B, Wiggins H. State of the Arctic conference 2010: international perspectives on progress of research responsive to decision-makers' information needs. *Ambio*. 2011;40: 824–7. doi: 10.1007/s13280-011-0153-5.

Hands across the ice. *The Economist* (London). 1996;Sep 21;340(7984):48.

Hitchins DRM. An Alaskan perspective. *Int'l J*. 2011; 66(4):971–7.

Huebert R. New directions in circumpolar cooperation: Canada, the Arctic Environment Protection Strategy, and the Arctic

Council. *Canadian Foreign Policy*. 1998;5(2):37–57. doi: 10.1080/11926422.1998.9673131.

Keskitalo C., et al. International region-building: development of the Arctic as an international region. *Coop Confl*. 2007;42(2): 187–205. doi: 10.1177/0010836707076689.

Koivurova T. Limits and possibilities of the Arctic Council in a rapidly changing scene of Arctic governance. *Polar Rec (Gr Brit)*. 2010;46(237):146–56. doi: 10.1017/S0032247409008365.

Koivurova T, Vanderzwaag D. The Arctic Council at 10 years: retrospect and prospects. *Univ B C Law Rev*. 2007;40(1):121–94.

Krauss S, Hussey KE. Arctic Council plan pushed would link 8 nations in joint effort: 2nd ed. Wash Times. 1995 Jan. 29 A.6.

Milne R. China wins observer status in Arctic Council. FT.com May 15, 2013.

Offerdal K. The EU in the Arctic. *Int'l J*. 2011;66(4):861–77.

Ottawa Declaration 1996. [Internet]. Arctic Council; 2013 [cited 12 Dec 2013]. Available from: <http://www.arctic-council.org/index.php/en/document-archive/category/5-declarations?download=13:ottawa-declaration>.

Pedersen T. Debates over the role of the Arctic Council. *Ocean Development and International Law*. 2012;43(2):146–56. doi: 10.1080/00908320.2012.672289.

The roar of ice cracking; outsiders in the Arctic. *The Economist* (London). 2013 Feb 2: Sect. 406: 49–50.

Staking our Arctic claim. Toronto Star (Canada). 2013 May 14:Sect. A:12.

Stokke OS, Hønneland G. *International cooperation and Arctic governance: regime effectiveness and northern region building*. London; New York: Routledge, 2006. p. 196.

Webster P. Health in the Arctic Circle. *The Lancet*. 2005; 365(9461):741–2. doi: 10.1016/S0140-6736(05)18003-9.

Young OR. Arctic tipping points: governance in turbulent times. *Ambio*. 2012;41(1):75–84. doi: 10.1007/s13280-011-0227-4.

Sources of Alaska Native Health Data and Statistics

Sigrid Brudie and Christy Garrett

Alaska Natives, as Alaska's indigenous people are known, live predominantly in rural communities with tiny populations, where small numbers make it difficult to collect meaningful health data. Information on the health status of Alaskans is mostly in the form of regional and state statistics. However, there are a few websites where data looking specifically at the health of Alaska Natives can be found. Those sites and their coverage are described here, starting with the most content-rich site regarding Alaska Natives.

Alaska Native Epidemiology Center (EpiCenter), Alaska Native Tribal Health Consortium (ANTHC)

<http://www.anthctoday.org/epicenter/data/index.html>



ANTHC's EpiCenter is 1 of 12 tribal epidemiology centers in the United States established by the Indian Health Service, the federal health program for American Indians and Alaska Natives. Data sharing is a core objective of the Center. The primary tool on the Health Data webpage is the Alaska Native Health Status Report, which provides data across a range of health indicators including adult and adolescent lifestyle risk factors, maternal and child health, cancer and cancer screening,

immunizations, diabetes, infectious diseases, environmental health, and dental health. The core document is a 2009 print report that can be downloaded from the Center's website and provides a statewide overview. An interactive map of Alaska allows the user to click on any of the state's 12 Tribal Health Regions to access data for that region.

On each region's page, there are three tabs from which to choose. The page opens in the "current data" tab, which provides one-page fact sheets in the form of PDF files organized into eight categories: demographics, mortality, morbidity, maternal and child, adult health, adolescent health, prevention, and "other data."

Each fact sheet contains the most recent data available on a specific health issue. For example, clicking "Interior Region" brings up 78 PDF files, including one called "Unintentional Injury Deaths." The fact sheet starts with a definition, i.e., "total number of deaths due to unintentional injuries per 100,000 persons," followed by the corresponding goal from Healthy People 2020 (10-year national health objectives outlined by the US Department of Health and Human Services), in this case to "reduce unintentional injury death rate to 36.0 per 100,000 persons." Next is a bulleted list summarizing relevant data for Alaska Natives in the Interior Region, followed by a graph and a table representing the data over a 20-year time period. Rates are compared for three groups—Alaska Natives in the region, Alaska Natives statewide, and US Whites—along with the Healthy People goal for that topic.

The "archived data" tab is currently empty for all regions but will eventually contain fact sheets and reports as they are replaced by newer ones.

The "full regional profile" tab provides a link to the most recent health status report for the region. Publication dates range from 2007 to 2012, with the Aleutians–Pribilofs Region report being the most recently updated. Average report length is 105 pages, and every report is full of data from a range of sources (Table 1).

ANTHC's EpiCenter is an essential starting point for anyone needing information on the health status of Alaska Natives.

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Table 1. Range of data found in regional profile reports.

Source	Data accessed from:
Alaska Native Tribal Health Consortium	Alaska Native Diabetes Registry Alaska Native Tumor Registry Division of Environmental Health and Engineering Immunization Registry Injury Prevention Program
State of Alaska	Alaska Trauma Registry Behavioral Risk Factor Surveillance System (BRFSS) Bureau of Vital Statistics Department of Labor and Workforce Development Pregnancy Risk Assessment Monitoring System (PRAMS) Section of Epidemiology, HIV/STD Program Youth Risk Behavior Survey (YRBS)
US Government	Centers for Disease Control and Prevention (CDC) Government Performance and Results Act (GPRA) Program Indian Health Service (IHS) National Data Warehouse National Cancer Institute's Surveillance, Epidemiology, and End Results (SEER) Program National Center for Health Statistics Substance Abuse and Mental Health Services Administration (SAMHSA) US Census Bureau

**Alaska Center for Health Data and Statistics,
State of Alaska Division of Public Health**

<http://dhss.alaska.gov/dph/infocenter/Pages/default.aspx>

The Alaska Center for Health Data and Statistics collects statewide information on births, deaths, newly diagnosed cases of cancer, injuries, occupational conditions and illnesses, and health behaviours. Information is categorized under 20 “topics of public health importance,” from alcohol use to food safety. For example, clicking on the topic “obesity/nutrition/physical activity” brings up approximately 30 links to State of Alaska program status reports, studies, guides, fact sheets, and bulletins containing such data as “fruit and vegetable intake in Alaska” (2010 Alaska Department of Health and Social Services report).

State surveillance covers all Alaskans, so visitors to the site need to drill down to information specifically about Alaska Natives. A new tool on the website called “Informed Alaskans” makes it easier to find Alaska Native health data and statistics. It combines a database and query system with interactive maps for accessing data compiled by the Alaska Behavioral Risk Factor Surveillance System (BRFSS), a program put in place in 1991 as part of the Centers for Disease Control and Prevention’s efforts to track health conditions and risk behaviors in the United States. “Informed Alaskans” allows users to break out Alaska BRFSS data by region—Public Health Region, Metro–Micropolitan Statistical Area, Borough²–Census Area, or Tribal Health Region—and further by health indicator and by race, so that health data for Alaska Natives can be isolated and compared.

²Unlike other states, Alaska uses boroughs rather than counties as geographic designations.

An additional link on the Center’s website is to current and archived copies of the *Epidemiology Bulletin*, published since 1970 by the State of Alaska Section of Epidemiology. There are hundreds of bulletins indexed by category, many of which contain data on the health of Alaska Natives. For example, a bulletin from 2004 is entitled “Use of Traditional Foods in a Healthy Diet in Alaska: Risks in Perspective.” This two-volume issue of the bulletin contains extensive charts and tables documenting methylmercury and PCB concentrations in traditional Alaska Native food sources. A bulletin from November 2013 called “Huffing in Alaska” provides data from the Alaska Youth Risk Behavior Survey. It compares adolescent inhalant abuse rates by type of school (traditional, alternative, corrective), race (Hispanic, White, Alaska Native), and Alaska Public Health Region (Interior, Gulf Coast, Anchorage–Mat-Su, Northern, Southwest, Southeast).

A significant amount of Alaska Native health data can be found on the Alaska Center for Health Data and Statistics website, and as the “Informed Alaskans” tool is perfected it will become easier to compare State of Alaska’s Public Health Region data with ANTHC’s Tribal Health Region data.

**The Center for Alaska Native Health Research
(CANHR), University of Alaska, Fairbanks**

<http://www.uaf.edu/canhr/>

The Center for Alaska Native Health Research was established in 2001 through a five-year grant awarded by the [National Institutes of Health](#) to the University of Alaska, Fairbanks. The Center’s research focuses on metabolic disorders, nutrition, obesity, cancer, and mental health in Alaska Natives. For example, colorectal cancer

rates are high among Alaska Natives in northwest Alaska, and CANHR is intensifying its research into this disparity.

The Center conducts collaborative, community-based participatory research, encouraging tribal members to become coresearchers. CANHR has partnered with the [Yukon-Kuskokwim Health Corporation \(YKHC\)](#) on a number of projects. YKHC is a tribal organization that administers healthcare delivery to 58 rural communities in southwest Alaska. A recent CANHR–YKHC collaborative project dealt with suicide and substance abuse intervention efforts in Yup'ik communities in southwest Alaska. The goal was to explore how Alaska Native people use ancestral knowledge and cultural traditions to promote well-being in young people and their families.

The “Research Publications” page of the Center’s website contains many citations to articles, books, theses, and dissertations that report results from research conducted at the Center.

CANHR seeks to share data gathered through its research projects. For confidentiality and intellectual property reasons, a data access application and sharing agreement are required. A list of current and past projects is available on CANHR’s website as well as paperwork for requesting access to research data.

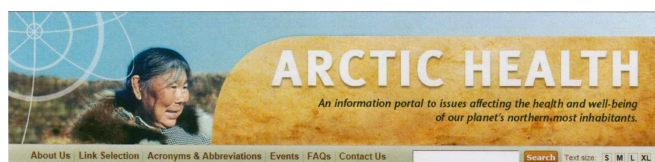
Circumpolar Health Observatory (CircHOB)

<http://circhob.circumpolarhealth.org/>

CircHOB is an international collaborative health information system that seeks to develop systematic, standardized, and consistent data collection and analysis for northern regions in all circumpolar countries, including health data on Alaska Natives. The Observatory is located at the Institute for Circumpolar Health Research in Yellowknife, NT. CircHOB has aggregated datasets from sources that include: Census and national population registries, vital statistics, morbidity and mortality datasets, and health surveys and other statistical reports. Subjects currently covered are population, fertility, mortality, reproductive outcomes, disease incidence, socioeconomic conditions, and health-related behaviors. The CircHOB website also offers interactive thematic mapping and graphing for selected datasets. Data are currently available for 2000–2009.

Arctic Health

<http://arctichealth.nlm.nih.gov/>



The Arctic Health website, managed jointly by the US National Library of Medicine and the Alaska Medical

Library at the University of Alaska Anchorage focuses on the health and well-being of Indigenous peoples of the circumpolar Arctic, including Alaska Natives. The site includes a growing section of links to health data sources. This complements other sections providing information about research conducted on climate change, food, air and water, and traditional healing. The site also has an extensive publications database, including grey literature that contains data from past health research projects. Other than the publications database, the site serves primarily as a portal, directing visitors through to other websites where the actual data can be found. In the “Research and Data” section, there are links to 18 research databases and portals that provide data as well as links to websites for 37 Arctic research groups where descriptions of current projects and contact information for principal investigators can be found. For example, on the “Research Organizations” page, one can find a link to the Institute for Circumpolar Health Studies website, where under “Research” then “Current Projects” there are descriptions of nine projects currently underway as well as researcher contact information. Current projects include “HIV/STI Evidence-Based Intervention for Alaska Native Communities,” “Social and Physical Determinants of Circumpolar Health: A Meta-Analysis,” and “Evaluating the Challenges to Self-Sufficiency Faced by TANF Clients in Alaska.” The site also contains reports from previous research projects.

Because this portal pertains to Arctic health in general, not all links relate to the health of Alaska Natives. Finding data and statistics on the Arctic Health website therefore requires some browsing and sifting, but with the site’s increasing focus on research and data it will likely become easier.

Conclusion

The researcher looking for Alaska Native health data and statistics is advised to start with the Alaska Native Epidemiology Center website as it is the most content-rich. For a comparison of Alaska Native health statistics with the general Alaska population, the new “Informed Alaskans” tool on the Alaska Center for Health Data and Statistics website is a helpful resource. The Center for Alaska Native Health Research does not provide open access to their research data but makes the data available through an application process. This might not be helpful for librarians or casual researchers looking for data, but there is a wealth of bibliographic information and project descriptions that can be accessed. Two websites that focus on health issues in the circumpolar north, Circumpolar Health Observatory and Arctic Health, are not specific to Alaska Natives, but the diligent searcher will find Alaska Native health data and statistics on those sites.

Research and data sources on Alaska Natives are becoming more numerous, and the hope is that access to the data will grow as well.

BOOK REVIEW / CRITIQUE DE LIVRE

Birth on the Land: Memories of Inuit Elders and Traditional Midwives. Edited by O'Brien B. Iqaluit, NU: Nunavut Arctic College; 2012. Softcover: 144 p. ISBN: 978-1-897568-10-1. Price: CAN\$26.25. Available from: <http://www.arcticcollege.ca/en/component/virtuemart/books/health-and-wellness-publications>

The impact and consequences of European contact and settlement on Canada's first peoples, including the widespread harm caused by the practices and policies of assimilation, are well known to us through investigations such as the Royal Commission on Aboriginal Peoples and the Truth and Reconciliation Commission. Less well known, perhaps, is the specific disruption to traditional birth practices and resulting social harm, particularly among the Inuit peoples. Two interventions impacted the traditional Inuit experience of pregnancy and birth: in the 1950s nurses and English-trained midwives began providing maternity care in community nursing stations and in the 1970s pregnant women began being removed from their families and communities and sent to southern hospitals for labour and delivery [1]. The damage caused by these practices to Inuit family and community has been recognized and has prompted the documentation of traditional Inuit birthing practices and efforts to re-establish the primary role of Inuit midwives and maternity care providers for birth support in the community [2]. Beverley O'Brien's *Birth on the land: memories of Inuit elders and traditional midwives* contributes to this focus. O'Brien was a nurse practitioner in the early 1980s in what is now Nunavut and had first-hand experience providing maternity care in the increasingly rare context of Elder-supported birth. Now a trained midwife and nursing professor at the University of Alberta, O'Brien has been involved with the recent development of a midwifery training program at Nunavut Arctic College to prepare Inuit maternity care providers to support women to give birth in their own communities.

The focus of this book are the memories, stories, and recollections of Inuit Elders and midwives from a very specific time, during the transition from birthing practices "on the land" to institutionalized birth in nursing stations and far-away urban centres. The book is a re-telling of interviews O'Brien conducted, with the help of Inuktitut or Inuinnaqun translators, with Elders and traditional midwives in 10 communities in Nunavut in 2010 and 2011. O'Brien's introduction to the book places birth in Nunavut in its historical and geographical context and describes the methodology she used to gather Elders' memories. She also describes the recent Nunavut government initiative to reclaim birth within communities. This has resulted in a new program at Nunavut Arctic College to prepare maternity care workers and midwives to support birth by respecting and utilizing traditional values while meeting Canadian maternity care standards.

As O'Brien indicates in her introduction, the book is not a comprehensive review of the history of all maternity care practices among the Inuit in Nunavut, but rather a collection of "snapshots" from a particular time in the life of the Elders and traditional midwives who shared their memories. O'Brien presents these conversations in six chapters organized around the themes reflected by the Elders' memories: Memories of life on the land, Memories of being pregnant on the land, Memories of birth on the land, Memories of the transition from birth on the land to institutionalized birth, Memories of caring for babies and children on the land, and Memories of adoption on the land. The emphasis on land underscores the Inuit relationship with their geography and environment in every aspect of life, including birth. Throughout the book are verbatim passages from Elders that frame O'Brien's discussion of Inuit traditional birthing practices and the transitions to institutionalized and medicalized birth. Each chapter provides snapshots of the interviewees' experience, whether it was her own birth and childhood, the stories of her parents' births, the births that she had supported as midwife, or the births of her own children, especially when those births changed from within the community to the isolation of southern hospitals. The seventh and final chapter, Sharing memories with contemporary midwifery students, focuses on the Elders' desire to see birth return to the community and their consideration of their own role in passing on the traditional birthing ways to the new students.

Although a brief 144 pages, *Birth on the land: memories of Inuit elders and traditional midwives*, is an important source of primary material. The first-person accounts provide rich detail of traditional Inuit ways surrounding childbirth and the impact of the new ways introduced by colonization. O'Brien's work in gathering the stories and memories of Elders respects the Inuit tradition of oral transmission of ways of knowing and practice. Given the age of the Elders and traditional midwives, it is fortunate that the work was done now while they are here to tell the stories. The central message of the book reiterates the quote from Nowyah Williams, Manager, Maternal Care, Rankin Inlet Birth Centre: "...a birth is a birth is a birth" (p. 23). For the Inuit birth was commonplace, part of life and part of the community, to be welcomed with little fuss and with the loving support of family and Elders, as it had been done for generations. O'Brien does well in demonstrating the impact of this loss to the family and community when mothers are separated by great distance for long periods of time to give birth and when the traditional relationship with Elders and respect for their wisdom has been supplanted by southern caregivers.

Two purposes and audiences might be served by this book. The first, as O'Brien suggests, is to provide grounding in traditional birthing practices for the midwifery training program at Nunavut College and to inform maternity care providers of the impact and contribution

of the Elders and traditional midwives. The role of Elders and the traditional midwives is well documented throughout the book and anyone who reads it will come away with more understanding and deeper appreciation of the place of birth in Inuit culture and the important roles these women played in families and the community. Chapter 3, *Memories of birth on the land*, provides fascinating, detailed descriptions of traditional birthing methods shared by the Elders on labour management and birth positions. Photographs were taken of Elders and volunteers demonstrating these traditional birth and support positions, including the practice of fundal pressure application, a procedure O'Brien notes as controversial in other settings. The photographs could be larger and better quality, but the images and text effectively describe the purpose, procedure, and outcome for these birth practices and could be incorporated, as O'Brien suggests, into training that respects the traditional Inuit ways as well as midwifery standards. Midwifery and other health professions students will not only benefit from these descriptions but also the book as a whole is a guide to culturally appropriate care.

The book's secondary role is for audiences outside of the health sciences looking at the impact of colonization on Inuit traditions and subsequent reclamation of traditional practices. This purpose is especially served by Chapter 4, *Memories of the transition from birth on the land to institutional birth*. As a scholarly source this book has some shortcomings such as no index, a need for more editing, and a very brief reference list that could be strengthened with more resources pertaining to the imposition of maternal health policies and the recent movement toward reclamation of traditional birth and returning birth to the land [3, 4]. Even with those gaps, the book's first-person accounts from the juncture of the entrenched practice of institutionalized birth and reclaiming of community birth contained are an important addition to our understanding of this era.

Any library that supports the study and teaching of midwifery, nursing, or obstetrics, especially where culturally competent care is part of the curriculum or Inuit or First Nations families are community clients, would do well to purchase this reasonably priced book. For other libraries, this book is a useful resource and addition to material exploring the traditional culture and subsequent impact of colonization and settlement on Canada's first peoples.

References

1. Van Wagner V, Epoo B, Nastapoka J, Harney E. Reclaiming birth, health, and community: midwifery in the Inuit villages of Nunavik, Canada. *J Midwifery Womens Health*. 2007; 52(4):384–91.
2. Couchie C, Sanderson S. Society of Obstetricians and Gynaecologists of Canada. A report on best practices for returning birth to rural and remote aboriginal communities. *J Obstet Gynaecol Can*. 2007;29(3):250–60.
3. O'Neil JD, Kaufert PA, Postl B, Binns B. A study of the impact of obstetric policy on Inuit women and their families in the Keewatin Region, NWT: final report, September 1990. Ottawa: Health and Welfare Canada; 1990. p. 58.
4. National Aboriginal Health Organization. Celebrating Birth – Aboriginal Midwifery in Canada. [Internet]. Ottawa: National Aboriginal Health Organization; 2008. [cited 18 November 2013]. p. 95. Available from: http://www.naho.ca/documents/naho/english/midwifery/celebratingBirth/Midwiferypaper_English.pdf

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BOOK REVIEW / CRITIQUE DE LIVRE

Knowledge Translation in Context: Indigenous, Policy and Community Settings. Edited by Elizabeth M. Banister, Bonnie J. Leadbeater, and E. Anne Marshall. Toronto: University of Toronto Press, 2011. Hardcover: 211 p. ISBN: 9781442641792. Price: CAD \$45.00. Available from: www.utppublishing.com

How can we systematically ensure that people apply evidence in practice? Within various fields, including the social sciences and health sciences, there is frustration that research findings are not translated into practical applications at the individual, population, or community levels. Banister, Leadbeater, and Marshall have compiled a text that attempts to overcome the “know-do” gap by outlining the barriers and facilitators of knowledge translation (KT) in the academic, policy, and indigenous community contexts. They emphasize a paradigm shift among academics–practitioners so that research knowledge is not valued over the community’s experience or contextual knowledge.

The 12 chapters in *Knowledge Translation in Context* focus on how knowledge translation is context dependent and context sensitive. The introductory chapter by Leadbeater, Banister, and Marshall lays the groundwork by adopting the Canadian Institute for Health Research (CIHR) definition of knowledge translation but expanding it to refer to all populations. They highlight the social disparities that exist within communities and the power imbalances and communication gaps that exist between researchers and consumers of research knowledge. Part I of the text focuses on partnerships between communities and academics. Part II focuses on the challenges of translating research findings into public policy. Part III focuses on how knowledge translation with indigenous communities could be improved by acknowledging cultural realities and employing integrated knowledge translation methodologies. Collectively, these parts of the text offer practical examples of barriers and facilitators of knowledge translation practices in academic–community settings, policy development, and indigenous contexts.

Part I: Community–University Contexts

Chapter 2 highlights some of the challenges faced by academics or researchers working with not-for-profit organizations that may have limited resources, high staff turnover, funding uncertainties, and shifts in priorities (as determined by stakeholders or boards). In such cases, the authors suggest using knowledge brokers in the KT process because they are trusted by all parties, understand the priorities of each partner, and forge partnerships that promote the use of evidence in decision making. Similarly, Marshall and Guenette (Chapter 3) acknowledge that there are multiple cultures and power dynamics involved in community-based research because there are differences

within multidisciplinary university-based research teams, within communities, and between academic researchers and the communities that they engage. They provide practical tips for engaging with these differences.

McGee (Chapter 4) suggests that if research information is tailored to the audience it will contribute to effective programs, operations, and policies. However, she also points out that some communities reject expert outsiders and are suspicious of researchers based on previous experiences. Using examples, the author suggests evaluative inquiry as a tool to engage in KT projects. Although this section encourages those in positions of power (academics) to initiate dialogue and build relationships with communities, it also points out that universities are rife with internal competition for grants and funding and there are power dynamics that value the contributions of some staff or faculty and specific departments (or even some research methodologies) over others. Few tips are provided for how academia can overcome these internal challenges.

Because local context is important for how practitioners implement research, Chapter 5 suggests that research flow must be considered a two-way street. The authors convincingly suggest that if KT is to succeed, practitioner interests must drive researchers’ questions and researchers must strive to share their research evidence (in the form of “actionable messages”) with practitioners. Practitioners face challenges in locating, accessing, and interpreting research evidence; therefore the authors suggest that knowledge brokers “summarize, distill, and disseminate knowledge to the field” (p. 85).

Part II: Policy Contexts

McCabe (Chapter 6) suggests that there are four reasons that research has limited influence on policy: (i) “information generated from research may be used for *negotiation* among competing interests rather than for the decision itself,” (ii) “research is not always comprehensive or convincing enough to inform policy,” (iii) “decisions are made without a formal decision making process,” and (iv) “policy makers may fall back on what they know because they may not know what information they need.” This chapter provides practical tips and concrete suggestions on how to engage policy makers with research. To alleviate KT barriers in policy contexts, it is suggested that knowledge brokers link knowledge production and knowledge use among policy makers and that scholars can educate policy makers about how to evaluate scientific findings and the meaning of the effects demonstrated by research. Finally, examples are provided of the types of documents (press releases and research briefs) that are effective for policymakers. Lenton (Chapter 7) provides a model for KT at the political level and reminds readers that change in government policy is a slow process. Chapter 8

presents a very tangible goal: to make reports of systematic reviews accessible to users. Practical suggestions include having users generate short user-friendly summaries and asking different user groups to create reviews of reports highlighting those recommendations that would be relevant to their roles and contexts.

Part III: Indigenous Contexts

Begoray and Banister (Chapter 9) suggest that effective KT with indigenous groups involves contextuality, collaboration, reciprocity, relationality, and reflexivity. In Chapter 10 the authors highlight how the Maori have always been involved in research, empirical observation, and theorizing but these may not conform to Western scientific concepts of objectivity and neutrality. Instead, the community favours a Maori-centered social constructionism. This framework is referred to as Kuapapa Maori Research as it integrates holistic, ecological, and communitarian approaches that enable communities to achieve their political aspirations of resistance to colonization and efforts to uphold sovereignty. Because context determines knowledge transfer, Smylie (Chapter 11) points out that it is crucial to pay attention to cultural protocols and practices when partnering with aboriginal communities given the history of colonization. She points out that “assumptions of modern-day biomedicine and epidemiology, combined with an emphasis on evidence based clinical practice and health care decision-making, contribute to a hierarchy of health knowledge in which Indigenous knowledge is devalued and marginalized” (p. 184). Instead, this text advocates for a community-based participatory action research model or CIHR’s integrated KT process where “stakeholders are involved in shaping the research questions, deciding on the methodology, helping with data collection and tool development, interpreting study findings, crafting the message and disseminating the research results” (p. 197). The closing chapter of the text identifies key facilitators and barriers to knowledge translation that must be considered in all KT efforts.

Analysis

This text provides an excellent example of how practitioners can overcome barriers to knowledge translation and learn from failures. The text was very relevant to my role as a clinical librarian at London Health Sciences Centre (LHSC), an acute care teaching hospital in London, Ontario. For instance, at LHSC, Continuous

Quality Improvement Councils regularly engage with librarians to inform their practice (via the literature search service and by soliciting publication support) as they design quality improvement initiatives that focus on improving patient care, reducing waste, minimizing cost, or resolving issues faced by frontline nursing and allied health professionals.

Some may consider the lack of an explicit reference to librarians a shortcoming of this text. However, most librarians often work as covert knowledge brokers as they may interact with staff from multiple disciplines or departments [1]. Although the authors do not specifically mention librarians, various chapters in this text acknowledge that knowledge brokering contributes to the success of KT. Librarians would benefit from reading this text to understand the gap that currently exists in turning research knowledge into practice and how they might play the role of a knowledge broker within their organizations. Many libraries already focus on making research accessible by creating subject guides or pathfinders, highlighting open access journals and encouraging publications in such journals, or by promoting institutional repositories. However, there may be a broader role for information professionals to collaborate in KT initiatives if they think of partnering with research units or of using networks to span boundaries and build bridges within and beyond their organization.

The authors of *Knowledge Translation in Context* provide an excellent framework for librarians, community practitioners, and researchers by aggregating diverse project experiences from around the globe to summarize the barriers and facilitators to KT. This text provides invaluable advice to researchers on how to be effective partners in the KT process. As such, this should be on the reading list of every practitioner or academic involved in community based quality improvement initiatives that attempt to bridge the “knowing–doing” gap.

Reference

1. Davenport TH, Prusak L *Working Knowledge: How Organizations Manage What They Know*. Boston, MASS: Harvard Business School Press; 1998.

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BOOK REVIEW / CRITIQUE DE LIVRE

An Invited Threat. Sanderson SK. Sanderson SK, illustrator; Muir S, editor; Van Camp R, copyeditor. Canada: Healthy Aboriginal Network; 2013. Softcover: 40 p. Price: CDN\$5.00. Available from: <http://www.thehealthyaboriginal.net/>.

Just a Story. Sanderson SK. Sanderson SK, illustrator; Muir S, editor. Canada: Healthy Aboriginal Network; 2012. Softcover: 48 p. Price: CDN\$5.00. Available from: <http://www.thehealthyaboriginal.net/>.

Kiss Me Deadly. Van Camp R. Auchter C, illustrator; Muir S, editor; Reimer V, copyeditor. Canada: Healthy Aboriginal Network; 2011. Softcover: 48 p. Price: CDN\$5.00. Available from: <http://www.thehealthyaboriginal.net/>.

Since the mid-2000s, the Healthy Aboriginal Network has been publishing comic books that address health and social issues in an aboriginal context.¹ Rather than present a single aboriginal reality, the authors, illustrators, and editors depict a multitude of individuals, experiences, attitudes, and beliefs, and they explore the intersections and tensions between them. The British Columbia based society describes its work as the “non-profit promotion of health, literacy and wellness” [1], a pursuit that is evident both in the comics that it publishes for Aboriginal youth and in its publishing practices: youth are invited to take part in focus groups that impact the final product, a practice that privileges their voices and creates opportunities for learning.²

Many of the issues addressed in the “Certified Aboriginal” comics are relevant both within and outside of Aboriginal communities. These include financial literacy, dog bites, residential school, maternal and child health, gangs, and fetal alcohol spectrum disorder [1]. The three comics selected for review—*Kiss Me Deadly*, *An Invited Threat*, and *Just a Story*—address sexual health, diabetes, and mental health. These comics draw from wisdom rooted in a variety of approaches to life and health, and they incorporate Aboriginal traditions and beliefs.

Kiss Me Deadly, written by Richard Van Camp and illustrated by Christopher Auchter, addresses sexual health across generations and sexual orientations. Acceptance of and love for individuals with diverse sexual preferences is supported by the traditional view of two-spirited individuals. The comic also addresses issues related to the medicine wheel, protection against and testing for sexually transmitted infections, pornography, sex, and love.

An Invited Threat, written and illustrated by Steven Keewatin Sanderson, shifts between fantasy and reality to highlight risk factors and outcomes associated with diabetes. The comic focuses on the impact that parents

and band store managers can have on the health of their partners, children, and community members.

Just a Story, also written and illustrated by Sanderson, addresses mental health issues. It follows two young siblings as they struggle to cope with their parents’ constant fighting and drinking, one by turning inwards and the other by directing his feelings outwards in bouts of violence and anger. The comic emphasizes the availability of support, focusing primarily on the roles of teachers and counsellors. The comic also highlights some of the ways that individuals can communicate with each other (by writing or drawing, for example) when it is too difficult to talk.

Ultimately, these comics point to opportunities for positive change and growth, as when a character in *Kiss Me Deadly* asserts that she does not see a space for sexual health in the medicine wheel, and shares her desire to begin a dialogue on the subject between youth and health professionals.

Sexual health, diabetes, and mental health are important issues to many readers, but of particular significance to young Aboriginals, their loved ones, caregivers, and educators. The Public Health Agency of Canada reports that “... Aboriginal peoples are over-represented in the HIV epidemic and are being infected with HIV at a younger age than other Canadians” [2]. They also report that “Type 2 diabetes is more frequent among Aboriginal children and youth than among their non-Aboriginal counterparts” [3]. Aboriginal populations are also disproportionately affected by mental health issues; Health Canada reports, for example, that “First Nations youth commit suicide about five to six times more often than non-Aboriginal youth” [4]. These comics have the potential to communicate important health information to an at-risk and diverse group of readers and learners: the straightforward, jargon-free narratives are easy to follow, and the thoughtful combination of illustrations, language, symbols, and lettering highlights key points.

One of the many strengths of the comics is their ability to educate without seeming overly didactic. Language and imagery are easy to understand and seem designed to lightheartedly introduce serious issues, which may minimize barriers of understanding and fear and demystify potentially frightening procedures and practices. *Just a Story*, for example, explores different approaches to mental health counselling and explains that the “labels” applied to individuals by health professionals are tools used to develop treatment plans, not to stigmatize. *Kiss Me Deadly* presents misconceptions about testing for sexually transmitted infections before countering them with accurate accounts of actual processes. Colloquial language

¹Many comics may be previewed at <http://www.thehealthyaboriginal.net/>.

²Videos related to focus group testing and the creation of the comics are available at the HealthyAboriginal YouTube channel at <http://www.youtube.com/user/HealthyAboriginal>.

and bold images lend to the clarity of the messages. For example, one character tells another that testing involves a nurse who “puts a finger up your bum”; this statement is accompanied by an image of the clothed speaker bent over. Both visually and through words, the comics capture experiences that may be shared by readers, contributing to the relatability of the narratives.

Healthcare and education professionals and institutions are generally depicted as playing positive roles in Aboriginal health. Further, aboriginal individuals are shown to be key players in healthcare, as when in *Kiss Me Deadly* a young aboriginal woman seeks information from an aboriginal nurse about becoming a nurse herself. Tensions are also explored. In *An Invited Threat*, a guest speaker from the Ministry of Health attends a band meeting to discuss “... the threat of diabetes, especially in rural communities ... , where the diabetes rate is five times the national average.” She is met with resistance, but the conflict provides opportunities both within and outside of the comic for discussion of factors that may lead to diabetes and the consequences of unhealthy eating practices.

Significantly, most of the characters in these comics take responsibility for their own health and support the health of others, as well. *An Invited Threat* explores the many factors that contribute to unhealthy eating including the availability and affordability of healthy foods, the role of band stores as a “revenue source for the nation” and the pressure to make a profit, the hectic pace of life, the ubiquitous presence of junk food, and the targeting of children as consumers by companies that make junk food. There is no suggestion that the choice to commit to healthy eating is easy or without cost, but the potential price of not making that commitment—including diabetes and death—is made clear. Setting an example for readers, the protagonists make choices that support the good health of their family and community. In *Just a Story*, a girl learns about mental health support and how it can greatly improve quality of life. She shares this knowledge with her brother, leading to a better life for them both. This process of learning and sharing is presented in the comics as worthwhile and rewarding, and it may encourage similar behaviour in readers.

Although these comics incorporate and promote acceptance of different approaches to health, they are not without their shortcomings. For example, whereas *Kiss Me Deadly* addresses two-spiritedness, all of the reviewed comics feature predominantly heteronormative narratives. *Kiss Me Deadly* also seems to condemn some sexual practices. For example, several characters disparage certain sexual practices as “cheap.” Referring to pornography, one character asserts: “... those pictures. They turn love-making into something mean and ugly.” This sentiment is communicated visually through two images, one of a naked man and woman embracing and kissing and the other of a female dominatrix and a male in bondage gear. The latter image is positioned directly under the enlarged and bolded word “ugly.” Such messages risk shaming or alienating readers.

Also of concern are the nightmarish images featured in a vision in *An Invited Threat*. Such images are common to comics, but the segment may be more likely to produce fear than understanding. In the vision, a woman sees herself attacked by a monstrous figure whose forearm and hand have been replaced by a menacing saw. The monster has been sent to amputate her legs due to “complications from [her] diabetes.” In the vision, the woman escapes before the monster reaches her, while in reality, some diabetics—including, perhaps, family members of the young readers—will need to undergo amputation due to diabetes complications. Although commendable for presenting visions as valid sources of knowledge and illustrating the serious consequences of diabetes and the possible anxieties of diabetics, the comic could negatively affect readers who may see a loved one or themselves in need of such a procedure.

Overall, the strengths of the comics greatly outnumber the weaknesses. The comics are easy to understand, relatable, affordable, and respectful of different approaches to life and learning in both their format and content. They make important health information accessible to a broad range of readers and connect readers to additional support and resources via a list of appropriate websites on their back covers. Healthy Aboriginal Network comics merit a place in any library that serves Aboriginal youth, and young people from other cultural backgrounds or the families, caregivers, or educators of these youth who may have an interest in the topics covered.

References

1. Healthy Aboriginal Network. The Healthy Aboriginal Network [Internet]. [cited 13 Jan 2014]. Available from: <http://www.thehealthyaboriginal.net/>.
2. Fact sheet: Aboriginal peoples [Internet]. Canada: Public Health Agency of Canada; Modified 30 August 2012 [cited 13 Jan 2014]. Available from: <http://www.phac-aspc.gc.ca/aids-sida/pr/sec6-eng.php#ab>.
3. Diabetes in Canada: facts and figures from a public health perspective. *Chapter 6 – Diabetes among First Nations, Inuit, and Métis populations* [Internet]. Canada: Public Health Agency of Canada; Modified 15 December 2011 [cited 13 Jan 2014]. Available from: <http://www.phac-aspc.gc.ca/cd-mc/publications/diabetes-diabete/facts-figures-faits-chiffres-2011/chap6-eng.php#THE1>.
4. First Nations & Inuit health. Mental health and wellness [Internet]. Canada: Health Canada; Modified 4 February 2013 [cited 13 Jan 2014]. Available from: <http://www.hc-sc.gc.ca/fniah-spnia/promotion/mental/index-eng.php>.

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PRODUCT REVIEW / ANALYSE DE PRODUITS

Evernote

Product Information: <https://www.evernote.com/>

Purpose: Cloud note management and web clipper (a tool for saving web content to view later)

Price: Basic account, free; premium subscription, \$5 per month or \$45 per year (USD)

Compatibility: Windows, Mac, iPhone–iPad, Android, BlackBerry, Windows phone

Product description

Evernote is one of the top tools for creating and organizing notes online. Notes are spaces where you can write text or upload an image or audio for future reference. Notes are saved and synchronized to your account, so you can view and edit them anywhere you can connect to the internet.

You can use Evernote to manage all of your life's notes such as grocery lists, to-do lists, wish lists, recipes, photos, and documents. Some people use it exclusively for work purposes to organize projects or to save pdfs and different webpages for research. I tested it for both work and personal uses. For work use, I made separate notes with details and links for each ongoing project. For personal notes, I saved recipes, products I want to buy, and gardening notes. I experimented with both creating notes from scratch and using the web clipper to save and edit pages from the web.

Evernote is a “freemium” service, with basic free (advertisement supported) accounts and an ongoing fee for premium accounts with extra features and no advertisements. It is available on all major platforms including desktop, web, and app versions, and I tested each.

Evernote has been available for a few years and has changed significantly since its initial release. I tried it a couple of years ago but found the interface unintuitive, and I was keen to give it another go.

Subscription options

You only need an email address to sign up for a free account. Premium accounts require a monthly or yearly fee but will enable:

- extra storage space (up to 100 MB for each note, 1 GB uploads per month),
- the ability to invite other people to edit your notes,
- optical character recognition (OCR) to make text in pdf files searchable,
- the ability to view and edit notes without an internet connection,
- the ability to view old versions of notes, and

- the search feature will include attached Microsoft Office documents.

I tested the free account for this review.

Features

Storage and syncing

Basic accounts allow up to 25 MB per note (about the size of five mp3s), and you can upload up to 60 MB a month. It autosaves notes as you edit them (you can turn this off if you prefer). Uploading a note adds it to your account, and you can then organize it.

Organization and search

Notes can be organized by tags, subtags, or geolocation and arranged into folders (which can further be arranged into stacks—basically another kind of folder). You can search within your saved notes by keywords, geolocation, or tag. Images you upload will be scanned with OCR to make the words searchable (OCR on pdf files requires a premium account).

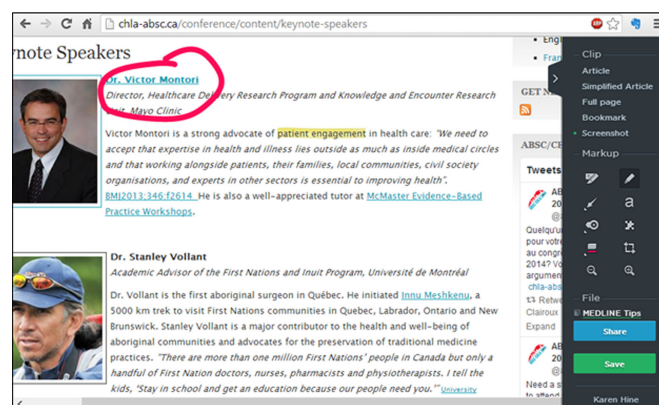
Web clipper

One of the best features of Evernote is the free add-on browser extension called Evernote Web Clipper (works with Google Chrome, Mozilla Firefox, Safari, and Internet Explorer). Once installed, you can select a web page (or part of a web page) to save as a note with just a couple of clicks, and you can even add your own markup. This makes it a convenient tool for saving things to read later (Figure 1).

Text editing

The text editor is robust and you can select most popular rich text features. The app version is the most limited, and it only allows bold, italic, strikethrough, and bullets and

Fig. 1. Web clipper.



numbering. The web version gives you a few extra options such as different font styles, colors, and sizes. The desktop version offers even more such as the ability to create tables.

Audio

Using the app and a device with a microphone, you can either record audio notes to add as an attached file or have the app transcribe spoken audio using speech-to-text. You can record for over two hours (long enough for many meetings). You can also upload saved audio files such as songs.

Images

You can easily attach images to notes from your desktop or the web. Using the app you can snap and upload pictures from your mobile device's camera and annotate them.

Other files

You may attach Microsoft Word documents and other files to notes, but you can't edit them without a compatible program.

Sharing

You can create a link to a note to share with people you choose. Anyone with the link will be able to view the note (they don't need an account). Only premium accounts will enable shared notes to be edited (this might be useful for collaborating on projects between colleagues or family members).

Integration with other services

It's easy to send content from other apps and websites to Evernote. For example, you can use your email account or Twitter to send notes to your Evernote. Or you can set up your Evernote so that it archives certain tweets for you. It integrates with other Evernote apps such as Hello (contact manager) and third party apps such as Penultimate (for taking notes by handwriting).

Reminders

You can elect to receive reminders or simple to-do lists about particular notes via app or email.

Security

In addition to the password, you can enable two-step verification (receive codes to log in by SMS or app). You can also view a history of when your account was accessed over the past 30 days.

Comparison with similar products

Springpad

Springpad offers a similar cloud note management tool with a web clipper and app. This tool is supported by advertising only (no premium accounts), so users cannot upgrade for extra features. It works mostly like Evernote and has the same note size limit, but it offers a more image-oriented interface. However, it lacks Evernote's advanced web clipper, OCR, editing features, and integration with other apps. Its main benefit is that it allows free (limited) collaboration on shared notes, and you can select certain notes to be public (so other people can discover them by searching or browsing and reshare). However, in terms of

picture or link-sharing communities, I prefer to use Pinterest or Tumblr for their larger size and usability.

Microsoft OneNote

Evernote's other's top competitor. OneNote's web and app versions are free, but the desktop version must be bought (either alone or it comes with Microsoft Office suite bundles, and there is also a 30-day free trial). You can download a web clipper for Internet Explorer only. Third-party extensions have been created for both Firefox and Chrome, but unfortunately these don't appear to be fully reliable. It integrates well with Microsoft products such as Office files, Outlook, and SkyDrive. Like Evernote, it does OCR. It also allows free real-time collaboration. The app is a bit more limited than Evernote in terms of its ability to organize notes, you can't store audio, and you must pay extra for storing more than 500 notes. This is a decent tool whose biggest limitations are the weak app and limited compatibility with different platforms and services.

Catch Notes

A decent freemium tool with a web version, web clipper, and app. Catch Notes boasts inline tagging for advanced note organization. Like Springpad, it also offers free PIN protection and (limited) collaboration, but not much else in the way of unique features. It limits you to plain text, and lacks Evernote's OCR and Springpad's social tools. The storage plans are expensive, and it does not mesh with as many apps and platforms as Evernote.

Google Drive

A freemium file creation and cloud storage tool with a different focus. It has a high storage limit of 5 GB and no limit per document or per month. The web interface boasts even more text editing options than Evernote's desktop version (footnotes, highlighting, etc.), and it will let you create tables, unlike Evernote's web version. It is also the only tool profiled here that will let you create and edit spreadsheets, even via the app. It also allows free real-time collaboration and OCR. Unfortunately, it lacks a web clipper and the ability to tag notes.

Google Keep

Newcomer Google Keep is very basic in its capabilities and is not currently compatible with many apps. From the web version you can upload notes and images but not audio, and storage space is shared with your drive. You can upload audio from the app and have it transcribe the words. Again, there is no web clipper and no tagging.

Figure 2 offers a comparison of the various tools, and Figure 3 outlines the various costs of the tools.

Strengths of Evernote

- Excellent web clipper
- Unlimited overall storage
- Some advanced text editing features
- Can share notes and web clips with select users
- OCR in images (some free; pdf files require Premium version)
- Advanced options for organizing and searching notes
- Reminders

Fig. 2. Compatibility and modes of access.

Web Version	Web Clipper	Mobile App	Desktop App
Evernote	Chrome Firefox Safari Internet Explorer	Apple/iOS Android BlackBerry Windows Phone	Windows Mac No
Springpad	Chrome Firefox Safari Internet Explorer	Apple/iOS Android (3rd party BlackBerry) No (mobile web version)	No
Microsoft OneNote	(3 rd party Chrome) (3 rd party Firefox) No Safari Internet Explorer	Apple Android (3rd party BlackBerry Playbook) Windows Phone	Windows No No
Catch Notes	Chrome Firefox No Safari Internet Explorer	Apple/iOS Android (3rd party BlackBerry) No	No
Google Drive	No	Apple/iOS Android No No	Windows Mac No
Google Keep	No	No Android No No	No

Fig. 3. Prices and storage (prices shown in USD).

Web Version	Limits on Free Accounts	Premium Prices & Storage		
Evernote	Total: No /Note: 25 MB /Month: 60 MB	Amount	Month	Year
		1 GB/month 100 MB max file size	\$5	\$45
Springpad	Total: No /Note: 25 MB /Month: No	No		
Microsoft OneNote	Total: 7 GB (SkyDrive) /Note: 2 GB /Month: No 30 day free trial of desktop version App: 500 notes	Amount	Month	Year
		27 GB total 57 GB total 107 GB total	No No No	\$10 \$25 \$50
Catch Notes	Total: 250 MB /Note: 20 MB /Month: 70 MB 3 spaces/notebooks	Amount	Month	Year
		1 GB/month 50 spaces/notebooks 5 GB/month 10 GB max file size 200 spaces/notebooks	\$5 \$16	\$45 \$145
Google Drive	Total: 15 GB (30 GB for enterprise Google Apps users) /Note: 2 MB (documents) 20 MB (spreadsheets) 50 MB (presentations) 10 GB (other files) /Month: No	Amount	Month	Year
		25 GB total 100 GB total 200 GB total 400 GB total 1 TB total 2 TB total 4 TB total 8 TB total 16 TB total	\$2.50 \$5 \$10 \$20 \$50 \$100 \$200 \$400 \$800	\$30 \$60 \$120 \$240 \$600 \$1200 \$2400 \$4800 \$9600
Google Keep	Total: 15 GB /Note: No /Month: No	Same as Google Drive		

- Desktop version has keyboard shortcuts to speed up work
- Excellent integration with third party apps

- Compatible with many platforms
- Advertisements are unobtrusive
- Two-step verification security for accounts

Weaknesses of Evernote

- Monthly data upload limit and file size limit might be too low for some purposes, even with the premium account
- No free collaboration
- No public note sharing or discovery
- Occasional glitches such as note previews not reflecting correct content
- Sometimes text is sluggish to edit

Conclusion

If you just need cloud file storage, skip Evernote—you'll get more space for less money with Microsoft OneNote (SkyDrive). Google Drive is slightly more expensive but it allows bigger files and lets you buy more storage. Amazon Cloud Drive is somewhere in between. Although Evernote has unlimited total storage unlike these alternatives, even the premium accounts have a monthly limit for how much you can upload.

If all you need is a place to create detailed documents on the web, you may prefer Google Drive's editing features. Unlike Evernote, it will also let you create spreadsheets and slideshow presentations and not just attach them. Also use Google Drive (or Box) if you're keen on free real-time collaboration. If you want to share with a broad public audience, Pinterest is great for short notes and links.

However, when it comes to creating, collecting, and organizing a variety of content in one place, Evernote is king. This feature-rich product is further enhanced by its compatibility with many third party apps. I use Evernote for most of my work and personal notes, and Pinterest just for ones I want to share publicly, such as recipes. I'm happy with this arrangement—but given how quickly these services can change in a couple of years, I'll be keeping an eye on the alternatives.

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Current Research

Compiled by Christie Hurrell

Carla Treloar, Rebecca Gray, Loren Brenner, et al. Health literacy in relation to cancer: addressing the silence about and absence of cancer discussion among Aboriginal people, communities and health services. *Health and Social Care in the Community* 2013;21(6): 655–664. doi: 10.1111/hsc.12054.

Cancer outcomes for Aboriginal Australians are poorer when compared with cancer outcomes for non-Aboriginal Australians despite overall improvements in cancer outcomes. One concept used to examine inequities in health outcomes between groups is health literacy. Recent research and advocacy have pointed to the importance of increasing health literacy as it relates to cancer among Aboriginal people. This study examined individual, social, and cultural aspects of health literacy relevant to cancer among Aboriginal patients, carers, and their health workers in New South Wales. Qualitative interviews were conducted with 22 Aboriginal people who had been diagnosed with cancer, 18 people who were carers of Aboriginal people with cancer, and 16 healthcare workers (eight Aboriginal and eight non-Aboriginal health workers). Awareness, knowledge, and experience of cancer were largely absent from people's lives and experiences until they were diagnosed, illustrating the need for cancer awareness raising among Aboriginal people, communities, and services. Some beliefs about cancer (particularly equating cancer to death) differed from mainstream Western biomedical views of the body and cancer and this served to silence discussion on cancer. As such, these beliefs can be used to inform communication and help illuminate how beliefs can shape responses to cancer. Participants proposed some practical strategies that could work to fill absences in knowledge and build on beliefs about cancer. These results were characterised by a silence about cancer, an absence of discussions of cancer, and an acknowledgement of an already full health agenda for Aboriginal communities. To promote health literacy in relation to cancer would require a multi-layered programme of work involving grass-roots community education, workers and Board members of Aboriginal community-controlled health organisations, and speciality cancer services, with a particular focus on programmes to bridge community-based primary care and tertiary level cancer services.

Geary J, Jardine CG, Guebert J, Bubela T. Access and benefits sharing of genetic resources and associated

traditional knowledge in northern Canada: understanding the legal environment and creating effective research agreements. *International journal of circumpolar health* 2013;7210.3402/ijch.v72i0.21351. PMID: 23986896; PMCID: PMC3754551.

Background: Research in northern Canada focused on Aboriginal peoples has historically benefited academia with little consideration for the people being researched or their traditional knowledge (TK). Although this attitude is changing, the complexity of TK makes it difficult to develop mechanisms to preserve and protect it. Protecting TK becomes even more important when outside groups become interested in using TK or materials with associated TK. In the latter category are genetic resources, which may have commercial value and are the focus of this article.

Objective: This article addresses access to and use of genetic resources and associated TK in the context of the historical power-imbalances in research relationships in Canadian north. **Design:** Review. **Results:** Research involving genetic resources and TK is becoming increasingly relevant in northern Canada. The legal framework related to genetic resources and the cultural shift of universities towards commercial goals in research influence the environment for negotiating research agreements. Current guidelines for research agreements do not offer appropriate guidelines to achieve mutual benefit, reflect unequal bargaining power, or take the relationship between parties into account. **Conclusions:** Relational contract theory may be a useful framework to address the social, cultural and legal hurdles inherent in creating research agreements.

Wilson D, de la Ronde S, Brascoupe S, et al. Health professionals working with First Nations, Inuit, and Metis consensus guideline. *Journal of obstetrics and gynaecology Canada*. 2013;35(6): 550–558. PMID: 23870781.

Objective: Our aim is to provide health care professionals in Canada with the knowledge and tools to provide culturally safe care to First Nations, Inuit, and Metis women and through them, to their families, in order to improve the health of First Nations, Inuit, and Metis. **Evidence:** Published literature was retrieved through searches of PubMed, CINAHL, Sociological Abstracts, and The Cochrane Library in 2011 using appropriate controlled vocabulary (e.g., cultural competency, health

services, indigenous, transcultural nursing), and key words (e.g., indigenous health services, transcultural health care, cultural safety). Targeted searches on subtopics (e.g., ceremonial rites and sexual coming of age) were also performed. The PubMed search was restricted to the years 2005 and later because of the large number of records retrieved on this topic. Searches were updated on a regular basis and incorporated in the guideline to May 2012. Grey (unpublished) literature was identified through searching the websites of selected related agencies (e.g., Campbell Collaboration, Social Care Online, Institute for Healthcare Improvement). **Values:** The quality of evidence in this document was rated using the criteria described in the Report of the Canadian Task force on Preventive Health Care (Table 1).

Lauren Baba. Cultural Safety in First Nations, Inuit and Métis Public Health. *National Collaborating Centre for Aboriginal Health* 2013; Prince George, BC. <http://www.nccah-ccnsa.ca/en/publications.aspx?sortcode=2.8.10&publication=88>.

This report provides an in-depth look at the state of cultural safety knowledge in Aboriginal health care, including such things as terminology, core competencies, accreditation standards, undergraduate and graduate level curriculum, professional development and continuing education opportunities, and provincial and national projects engaging with the issue.

Sarah O. Alkholy, Samiah N. Alqahtani, Audrey Cochrane, Maria Pontes, Fidgi Ferreira. Aboriginal and non-Aboriginal students learn about natural health products from different information sources. *Pimatisiwin: A Journal of Aboriginal and Indigenous Community Health* 2013;11(1): 99–112. http://www.pimatisiwin.com/online/?page_id=1144.

Natural health products (NHPs) include naturally derived botanical and nonbotanical products. Past research indicates a high prevalence of NHPs use amongst adults in the United States and Canada but does not clearly characterize NHPs use amongst students, ethnic variations of such use, or how users learn about NHPs. We hypothesize that there is a difference between Aboriginal

and non-Aboriginal students in how they learn about NHPs. To investigate this question, we conducted a cross-sectional study at First Nations University of Canada and the University of Regina, Saskatchewan, Canada, during the fall of 2011. Aboriginal (n = 214) and non-Aboriginal (n = 749) students participated in the 28 question survey. Our results indicate that Aboriginal students who use NHPs are found in all age groups, are mostly female, are smokers and nonsmokers, and learn about NHPs from Elders and healers. Compared to non-Aboriginal students, Aboriginal students rely significantly less on alternative and conventional health providers, electronic media, print media, and advertising as their sources of information about NHPs. Thus, Aboriginal students use Elders or healers as a primary source of information to learn about NHPs, as compared to non-Aboriginal students. Future work should investigate the role of Elder traditional educators to convey NHPs information directed specifically to Aboriginal university students.

Indigenous Health Advisory Committee and Office of Health Policy and Communications. Indigenous health values and principles statement. *Royal College of Physicians and Surgeons of Canada* 2013. http://www.royalcollege.ca/portal/page/portal/rc/common/documents/policy/indigenous_health_values_principles_report_e.pdf.

The wellbeing of Canada's indigenous people is a top priority for the Royal College. Our strategic plan explicitly sets out to improve the health and health care of Canada's Indigenous Peoples who have been identified as suffering the poorest health in Canada. The Royal College has produced this seminal document, *Indigenous health values and principles statement*, to foster understanding, dialogue, action and positive change in indigenous health.

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Online Sources of Aboriginal Health Information

Although the government closed the [National Aboriginal Health Organization](#) (NAHO) in June 2012, their web site remains online until the end of 2017. Despite critiques from First Nations, Metis, and Inuit groups of NAHO's ability to reflect the diversity of Aboriginal peoples in Canada, the web site remains an excellent repository of information on Indigenous health and wellness in Canada.

Various organizations provide similar coordination. The [National Collaborating Centre for Aboriginal Health](#) (NCCAH) and the [Institute of Aboriginal Peoples' Health](#) (IAPH) of CIHR are increasingly important both as sources of information and in building the knowledge base needed to advance Aboriginal health.

The [Health Libraries Wiki](#) (HLWIKI International), maintained by Dean Giustini, presents a comprehensive starting point for discussions of Aboriginal health. It includes theoretical perspectives and practitioner knowledge and points to key portals and databases.

Though it can hardly count as "news," the [Royal Commission on Aboriginal Peoples](#) Report, especially Volume 3: *Gathering Strength*, contains significant remarks on health and wellbeing. Many policies and programs noted in this issue have been guided by Commission recommendations.

The [Healthy Aboriginal Network](#) is an organization based in British Columbia that provides health information, including bilingual publications, for and by indigenous people. Promoting community-focused health literacy,

they have partnered with various authors (such as Richard Van Camp) to present comic books on issues around health and wellness—including sexuality, dog bites, and financial literacy. Three of their comics are reviewed in this issue.

The [Aboriginal Audio Digitization and Preservation Program](#) (AADPP) out of UBC Library's [Irving K. Barber Learning Centre](#) is a partnership with the Museum of Anthropology and the First Nations Technology Council. As an indigenous knowledge initiative, it is by nature interdisciplinary. Digitizing culturally significant teachings not only builds capacity in these communities, but also offers the opportunity to learn from elders about traditional health knowledge in a way that respects traditional means of communicating this knowledge.

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ANNOUNCEMENT / COMMUNIQUÉ



Scaling New Heights Together in 2014 at CHLA-ABSC in Montreal!

The 38th Annual CHLA-ABSC Conference in Montreal is fast approaching! From 16 to 20 June, 2014, an exciting program filled with five days of meetings, sharing of expertise and dissemination of ideas are awaiting health librarians from across Canada! The organizing committee is busy finalizing the last details that will make your stay a memorable experience.

Continuing Education

This year, three courses in French will be offered. The course “Veille informationnelle en santé: collecter, organiser et diffuser l’information” will introduce participants to the monitoring process, including concepts and methods that must be critically analyzed, along with tools that will meet a variety of needs and backgrounds. Elsa Drevon and Olivier Robert will focus on examples based on Best Practices adapted from the monitoring services offered at CHU Sainte-Justine and the National Public Health Institute of Quebec.

Do you understand the principles of evidence-based practice but aren’t quite sure how to apply them in a clinical setting? Monique Clar’s course, entitled “Pratique fondée sur des données probantes: atelier pratique” will guide you through structuring a clinical PICO question, while discovering relevant resources to support this process. It will also give you the opportunity to utilize PubMed more effectively throughout your searching for these evidence-based resources, all while understanding the levels of evidence, recognizing the various types of clinical

studies and using recommendation scales. Whew, what a busy morning!

Bénédicte Nauche and Tara Landry will present “La recherche documentaire en support aux revues systématiques: planification, méthodologie et outils”. Through hands-on examples, participants will have the opportunity to familiarize themselves with the requirements of the systematic review (SR) process and better understand their own role in supporting this research practice. All systematic review secrets will be revealed to you through this intensive workshop by understanding the standards, stages of production and planning, information retrieval and documentation of research.

The courses offered in English will allow you to explore other themes:

- Bioinformatics for Librarians (Natalie Clairoux);
- Introduction to Lean Management: Continuous Process Improvement in Healthcare and in the Library (Francesca Frati);
- Research by Design: Proposing, Planning, and Carrying Out a Research Project for the Practising Librarian (Lorie Kloda);
- Knowledge Management: An Introduction and Application to Healthcare (Kimiz Dalkir);
- EBM: Reviewing the Quality of the Studies (Connie Schardt).

For the schedule and rates for continuing education courses, check the [CHLA-ABSC conference website](#).

Networking

One of the most popular features of the CHLA–ABSC conference is its human dimension: You will not only leave with additional professional knowledge, but also with a list of new contacts. Is this your first time attending? Don't fear! The First Timers' Reception will allow you to meet other delegates, exhibitors and members of the Board of Directors and organizing committee. You will also have multiple opportunities to connect with colleagues from all over the country, whether it be during a jazz tune at the opening reception, a group dinner in a trendy restaurant or at the banquet in the ballroom of the Hyatt Regency. And last but not least, the spectacular DJ Christoph Kapp from Login Canada will host the official conference party, which will overlook La Place des Festivals and the Francolies.

Guided Tours

Do you know which building in Montreal has the most visitors? [La Grande Bibliothèque](#), which receives nearly 8,000 visitors per day! La Grande Bibliothèque is an important center of cultural influence of Bibliothèque et Archives nationales du Québec (BANQ), an institution whose mission is to acquire, preserve and disseminate archival documents, films and published documentaries surrounding the heritage of and/or about Quebec. Come discover the magic of this building, winner of a prestigious architectural award in 2007, with a visit highlighting public spaces, collections, services and activities offered at the Grande Bibliothèque. While visiting, stop by to see a selection of books on health specifically prepared for the occasion, which will be displayed in "La Collection Nationale" Reading Room during the duration of the conference.

The hospitality committee also invites you to discover the exhibition "[Where Montréal Was Born](#)" at the

[Pointe-à-Callière](#) Museum. You will be transported to the heart of an authentic archaeological site, the birthplace of Montreal, in an unusual underground route covering six centuries of history, from the times when indigenous people camped here to the present day.

The early registration ends soon!

[Sign up for the conference](#) before Thursday, May 15 to receive our discounted rate. Don't forget to [book your room](#) at the Hyatt Regency Montreal now to ensure you are in the heart of the action!

Join the conversation

Visit our website at chla-absc.ca/conference to be kept updated on all the conference details. Browse our selection of restaurants, sightseeing opportunities and shopping in Montreal. Share your experiences of the conference via our [Facebook group](#) and our Twitter account, [@abscchla14](#) and follow the hashtag [#abscchla14](#).

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Gravir ensemble de nouveaux sommets au congrès 2014 de l'ABSC-CHLA à Montréal!

Le 38^e congrès annuel de l'ABSC-CHLA à Montréal approche à grands pas! Du 16 au 20 juin 2014, cinq jours de rencontres, de partage d'expertise et de diffusion d'idées réuniront les bibliothécaires de santé du Canada, grâce à un programme emballant. Le comité organisateur s'affaire à finaliser les derniers détails qui feront de votre séjour une expérience mémorable.

Formation continue

Cette année, trois cours en français vous sont proposés. D'abord, le cours "Veille informationnelle en santé: collecter, organiser et diffuser l'information" présentera aux participants, pour chaque étape d'un processus de veille, les concepts et les méthodes qu'il convient de maîtriser, ainsi que certains outils dont les multiples possibilités d'agencement permettront de répondre à une grande variété de besoins et de milieux. Elsa Drevon et Olivier Robert animeront cette journée qui mettra l'accent sur des exemples de bonnes pratiques, issus de l'expérience des services de veille offerts au CHU Sainte-Justine et à l'institut national de santé publique du Québec.

Vous connaissez les principes de la pratique factuelle mais hésitez à les appliquer dans un contexte clinique? Le cours de Monique Clar, "Pratique fondée sur des données probantes: atelier pratique", vous permettra de structurer une question clinique PICO, d'utiliser des sources documentaires pertinentes et de configurer PubMed en fonction d'un meilleur accès aux données probantes, de reconnaître les types d'études cliniques et de comprendre les niveaux de preuve et échelles de recommandation. Une matinée bien remplie!

Enfin, profitez des sages conseils de Bénédicte Nauche et de Tara Landry présentés dans le cours "La recherche documentaire en support aux revues systématiques: planification, méthodologie et outils". À travers exemples et exercices, les participants auront l'opportunité de se familiariser avec les exigences de la recherche documentaire en support aux revues systématiques (RS) et de mieux comprendre leur propre rôle. Grâce à cette journée de formation, les standards, les étapes de production d'une RS, la planification, la recherche documentaire et la documentation de la recherche n'auront plus de secrets pour vous!

Les cours offerts en anglais vous permettront d'explorer d'autres thématiques:

- Bioinformatics for Librarians (Natalie Clairoux);
- Introduction to Lean Management: Continuous Process Improvement in Healthcare and in the Library (Francesca Frati);
- Research by Design: Proposing, Planning, and Carrying Out a Research Project for the Practising Librarian (Lorie Kloda);
- Knowledge Management: An Introduction and Application to Healthcare (Kimiz Dalkir);
- EBM: Reviewing the Quality of the Studies (Connie Schardt).

Pour connaître l'horaire et les tarifs des cours de formation continue, consultez le [site web du congrès ABSC-CHLA](#).

Réseautage

Une des caractéristiques les plus appréciées du congrès de l'ABSC-CHLA est sa dimension humaine - vous en repartirez avec un bagage professionnel additionnel, mais également avec une liste de nouveaux contacts. Ce sera votre première fois? Pas d'inquiétude! La réception pour les premiers congressistes vous permettra de rencontrer les autres délégués, exposants et membres du Conseil d'administration et du comité organisateur. Autrement, vous aurez de multiples occasions de renouer avec vos collègues de tous les coins du pays et de faire de nouvelles rencontres: sur un air de jazz lors de la réception d'ouverture, au cours d'un souper de groupe dans un restaurant branché, ou pendant le somptueux banquet dans la salle de bal du Hyatt Regency. Enfin, comme le veut la tradition, le spectaculaire DJ Christoph Kapp de Login Canada animera le party officiel du congrès dans une salle surplombant la Place des Festivals et les Francolies.

Visites guidées

Savez-vous quel bâtiment est le plus visité à Montréal? Il s'agit de la [Grande Bibliothèque](#), qui reçoit près de 8 000 visiteurs par jour. La Grande Bibliothèque est un important centre de rayonnement culturel de Bibliothèque et Archives nationales du Québec (BAnQ), une institution qui a pour missions d'acquérir, de conserver et de diffuser le patrimoine documentaire publié, archivistique et filmique

du Québec ou relatif au Québec. Découvrez ce qui fait la particularité de cet édifice, lauréat d'un prestigieux prix d'architecture en 2007, au cours d'une visite mettant en lumière les espaces publics, les collections, les services et les activités offerts à la Grande Bibliothèque. Profitez également de votre visite pour consulter une sélection d'ouvrages sur la santé préparée spécialement pour l'occasion, dont certains seront exposés dans la salle de lecture de la Collection nationale pendant la durée du congrès.

Le comité hospitalité vous invite également à découvrir l'exposition *Ici naquit Montréal* au [Musée Pointe-à-Callière](#). Vous serez transporté au cœur d'un site archéologique authentique: le lieu de fondation de Montréal, dans un parcours souterrain inédit qui couvre six siècles d'histoire, de la période amérindienne à nos jours.

L'inscription anticipée se termine bientôt!

[Inscrivez-vous](#) au congrès avant le jeudi 15 mai afin de profiter du tarif réduit. [Réservez](#) également votre chambre au Hyatt Regency Montréal dès maintenant, afin de vous assurer d'être au cœur de l'action!

Participez à la conversation

Visitez notre site Web à l'adresse chla-absc.ca/conference/fr pour connaître tous les détails et nouvelles du congrès. Parcourez nos sélections de restaurants, de visites touristiques et de magasinage à Montréal. Partagez vos expériences du congrès via notre [groupe Facebook](#) et notre compte Twitter, [@abscchla14](#), et suivez le mot-clic [#abscchla14](#)

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