## **NH ETHICS PRACTICE MODEL**

Building Together an Ethically Strong Organization

NH Ethics Service

2023



# **Document Control**

Document Title	NH Ethics Practice Model: Building Together an Ethically Strong Organization				
Document Sign-Off					
Principal Reviewers	Kirsten Thomson BSc(Pharm) LLB MBA CRM Regional Director, Legal Affairs, Enterprise Risk & Compliance, Chief Privacy Officer	Kirsten.Thomson@northernhealth.ca			
Principal Author	Dr. Esther Alonso- Prieto, Ethics Lead	Esther.AlonsoPrieto@northernhealth.ca			
Contributing Authors					
Version History	V1.0 2022-July-03	First draft reviewed by Working Group (Feedback received from Julia Bickford and Melanie Maracle)			
	V1.1 2022-Aug-04	Second Draft reviewed by Ethics Committee Members			
	V2.0 2023-Feb-01	Third Draft reviewed by Ethics Committee Members			



# **Table of Contents**

Do	ocume	nt Control	2
1.	Intr	oduction	4
2.	NH	Ethics Service: Structure and Overarching Goals	4
3.	C.O	.R.E. Areas of Service	5
	3.1.	Clinical Ethics	5
	3.2.	Organizational Ethics	5
	3.3.	Research Ethics	6
	3.4.	Education	8
4.	Ethi	ical Approaches Adopted by NH	9
5.	Pro	moting and Embedding Reconciliation in Health Care: the NH Approach	11
6.	Con	clusions	12
7.	Refe	erences	13
8.	App	endixes	17
	Appen	ndix 1 - Northern Health Authority Ethics Committee, Terms of Reference	17
	Appen	ndix 2 - Northern Health Authority HSDA Ethics Committees, Terms of Reference	20
	Appen	ndix 3 – Northern Health Research Ethics Board, Terms of Reference	25
	Appen	ndix 4 - NH Ethics Service Structure	31
	Appen	ndix 5 - NH Method for Decision-Making in Clinical Ethics	32
	Appen	ndix 6 - NH Method for Decision-Making in Organizational Ethics	33
	Appen	ndix 7 – Organizational Decision-Making – Ethical Considerations	35
	Appen	ndix 8 — Surge Capacity Decision-Making Model	36
	Appen	ndix 9 — Surge Capacity Decision-Making Model — Abridged	37
	Appen	ndix 10 - Operational Approval Decision-Making Guideline	38
	Appen	ndix 11 - Ethical Values which NH Upholds	39



#### 1. Introduction

The "Northern Health Ethics Practice Model: Building Together an Ethically Strong Organization" is the foundational document that defines and enables the Northern Health (NH) approach to moral integrity. It also articulates the mandate of the NH Ethics Service.

NH staff are encouraged to use this document together with their own professional ethics codes to guide their behaviour and decisions.

This "Ethics Practice Model" has been developed by the NH Ethics Service with input from patients, clients, families, staff members and the Ethics Committees. The Service is also accountable for disseminating and revising this document.

The document is divided in 8 sections. Sections 2 and 3 introduce the NH Ethics Service, clarifies its structure, and defines its commitments in each of the 4 C.O.R.E. areas of service. Section 4 explains the theoretical perspectives that inform NH ethical practice. Finally, Section 5 presents how NH Ethics Service understands and operationalizes its obligation to promote and embed reconciliation within organizational practices and operations. The decision-making guidelines, which are included as appendixes at the end of the document, translate the values and approaches adopted by NH into real-life applications.

## 2. NH Ethics Service: Structure and Overarching Goals

Stemming from its vision of leading the way in promoting health and providing health services for Northern and rural populations, NH commits to build together an ethically strong organization. While this mandate is shared by all departments across NH, the Ethics Service has been specifically tasked with performing the functions required to operationalize it. To this end, NH Ethics Service pledges to provide high quality, standardized and timely services in four C.O.R.E. areas: Clinical, Organizational and Research Ethics as well as Education.

NH Ethics Service includes an Ethicist, and five ethics committees: the NH Ethics Committee, three regional Ethics Committees (North East, North West and North Interior), and the NH Research Ethics Board (REB). The Committees Terms of Reference are included in Appendixes 1, 2 and 3. The Service is accountable to the NH Governance and Management Relations (GMR) Committee of the Board (Appendix 4).

The Ethicist is responsible for leading all the activities of the NH Ethics Service and ensuring a consistent and coordinated approach to Ethics across NH. The Committees act as an advisory body to the ethicist in matters related to clinical and organizational ethics. The REB is responsible for reviewing, accepting, rejecting, and proposing modifications to all research studies conducted within the jurisdiction of NH or under its auspices.



#### 3. C.O.R.E. Areas of Service

#### 3.1. Clinical Ethics

<u>C</u>linical ethics is a practical discipline that provides a structured approach to assist health professionals in identifying, analysing, and resolving ethically challenging situations that arise during the clinical encounter with individual patients.

In this area, NH Ethics Service strives to:

- guide and support ethical practice; and
- embed ethics consultations in daily patient care.

These goals are operationalized by providing clinical ethics consultations<sup>1</sup> to patients, clients, families, health care providers and professionals, administrators, and leaders. During an ethics consultation, skills and knowledge from the traditions of ethics theories and dispute resolution are used to facilitate a rigorous analysis and create a space in which an authentic engagement between individuals immersed in different realities can occur (1). Ultimately, it is the patient, and the family together with the health care professionals who decide and act. However, the Ethics Service is responsible for supporting them and assisting them throughout the process.

During ethics consultations, the **NH Method for Decision-Making in Clinical Ethics** (Appendix 5) is used to guide ethics reasoning. When confronted with an ethical dilemma, NH staff are encouraged to systematically work through the steps outlined in that Method.

Historically, clinical ethics consultations have been requested reactively when the chances of implementing satisfactory action are significantly reduced. However, studies have shown that when ethics consultations are not reactive but embedded within daily clinical practice, the length of stay and expense of hospitalizations decrease (2-4); patient outcomes improve (5-7), particularly for patients at the end of life (8-11) and patients are transitioned more effectively to the most appropriate level of care (12). Therefore, the Ethics Service strives to improve institutional capacity and standardize resources for identifying and addressing clinical ethical issues as close to the point of care as possible.

#### 3.2. Organizational Ethics

With the rise of managed care, the fundamental unit of health care delivery has changed to include not only the patient-clinician dyad but also the health care organization itself. Thus, in conjunction with the individual perspective, an organizational perspective that incorporates the ethical dimension of health care operations has emerged.

In the area of **O**rganizational Ethics, NH Ethics Service strives to:

<sup>&</sup>lt;sup>1</sup> Clinical Ethics Consultation can be requested by emailing the ethicist at Ethics@northernhealth.ca



\_

- support health care teams to develop policies and guidelines rooted on the highest level of ethical standards;
- partner with managers and leaders to support decision-making processes that are open, transparent, inclusive, fair, accountable and grounded in explicit, collective values;
- assessing the ethical climate to identify system-level issues that impact quality of care and create ethical dilemmas at the individual patient level.

These goals are operationalized by providing organizational consultations<sup>2</sup> to all levels of management, that is, senior, middle, and frontline management. During these consultations, the theoretical approaches that inform ethical discernment at NH (Section 3) are integrated with best decision-making practices to create a structured and robust decision-making guideline. This guideline is presented in Appendixes 6 and 7. NH staff is encouraged to use it systematically to guide their health care management decisions.

Importantly, NH recognizes the specific ethical challenges that leaders confront when making and implementing decisions under surge capacity requirements. That is why, a surge capacity decision making guideline has also been created. This model, which is presented in Appendixes 8 and 9, can help leaders to address issues such as diversion, staffing, introducing modifications to standards of care.

NH Ethics Service goals in the area of Organizational Ethics are also operationalized by performing environmental scanning, that is, gathering, and interpreting information about the moral landscape in which NH operates to identify vulnerabilities and strengths and suggest practices, structures, and policies that could be modified or introduced. This way, it is recognized that ethics cases are embedded in, and influenced by, a larger organizational context and a bridge is built between Clinical and Organizational Ethics.

As part of its role in assessing the ethical climate and supporting the development of an ethically strong organization, NH Ethics Service also provides support to Human Resources and other professional bodies responsible for furthering staff ethical behaviour in accordance with Northern Health Standards of Conduct. In this case, the nature and tone of the NH Ethics Service involvement are facilitative and egalitarian and aims to encourage group dialogue and understanding.

#### 3.3. Research Ethics

In the area of **R**esearch Ethics, NH Ethics Service strives to:

support the activities of the NH REB;

<sup>&</sup>lt;sup>2</sup> Organizational Ethics Consultation can be requested by emailing the ethicist at Ethics@northernhealth.ca



\_

 ensure that all research conducted under the jurisdiction of NH adheres to the highest ethical standards and is consistent with Canadian and international policies and guidelines.

The ethical standards of the Canadian clinical research enterprise are rooted in the ethics lodestars of modern clinical research: the Nuremberg Code, the Declaration of Helsinki, the Belmont Report, the International Conference on Harmonization of Technical Requirements for Registration of Pharmaceuticals for Human Use (ICH) guidelines, and the Council of International Organizations of Medical Sciences (CIOMS).

The current official research ethics policy in Canada is outlined in the Tri-Agency Framework: Responsible Conduct of Research (RCR) (13) and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans (TCPS2) (14). These guidelines were developed jointly by the three research government agencies, Canadian Institute of Health Research (CIHR), Natural Sciences and Engineering Research Council of Canada (NSERC) and Social Sciences and Humanities Research Council (SSHRC) and although they do not have the force of law, they are nationally adopted and must be strictly followed by researchers and institutions who receive funding from these Agencies.

The RCR informs investigators and their institutions of their obligations to promote and maintain research integrity and outlines policies related to requesting and administering funds, performing research, disseminating results, defining and addressing misconduct, and policy breaches and reporting to the Agencies (13). TCPS2 guides "the ethical aspects of the design, review and conduct of research involving humans" (14). It is entrenched on the cardinal value of modern research ethics, respect for human dignity, as expressed through three core principles: respect for persons, concern for welfare, and justice. Guided by these principles, TCSP2 provides guidelines to ensure that participants' autonomy and wellbeing are protected, that vulnerable populations are not exploited, that personal information are kept private, confidential, and secure, that the burdens and benefits of research are equitably and justly distributed, and that all clinical trials are publicly registered prior to recruiting participants. Additionally, TCPS2 sets the standards for Canadian Research Ethics Boards (REBs).

Health Canada also defines the obligations that sponsors, and researchers must fulfill when investigating and marketing drugs (Food and Drugs Regulations) and devices (Medical Devices Regulations). The regulatory process is conducted by the Health Products and Food Branch (HPFB) under the authority of the Food and Drugs Act and its associated Food and Drugs Regulations (15). Health Canada regulations integrate the principles of Good Clinical Practice (GCP) as described by the ICH E6 (R2), which are also consistent with TCPS2.



There are also federal and provincial laws and regulations NH observes when collecting, using or disclosing personal information in health research. At the federal level, privacy protection laws include the Canadian Charter of Rights and Freedoms (16), the Personal Information Protection and Electronic Documents Act (PIPEDA) (17) and the Privacy Act (18). At the provincial level, BC has enacted the Personal information Protection Act (PIPA) (19), which is considered to be "substantially similar" to PIPEDA. There are two additional documents with a special focus on clinical research that provide national direction on information privacy matters: TCPS 2 (14) and the CIHR Best Practices for Protecting Privacy in Health Research (CIHR BPPP) (20).

NH investigators should also comply with specific regulations stipulated by countries with which they establish scientific collaborations. For example, the USA requires investigators to comply with U.S. Food and Drug Administration (FDA) regulations, while the European Union requires compliance with the requisites set by the European Medicines Agency and the member state where the research takes place.

The above-mentioned ethical guidelines and research policies are enacted at NH through the NH REB<sup>3</sup>. In accordance with TCPS, the REB is independent in their decision making and is accountable to the NH Governance and Management Relations (GMR) Committee of the Board. NH Ethics Service directs and coordinates the activities of the NH REB.

As part of its functions supporting Research Ethics, NH Ethics Service also facilitates the operational review process of scientific studies. This process objectively assesses the operational demands that research studies may impose on NH. Operational approvers are encouraged to consult the "Operational Approval Decision-Making Guideline" (Appendix 10) when deciding whether a proposed research can be supported by the relevant departments within NH.

#### 3.4. Education

Ethical problems in everyday health care work emerge for many reasons. One of them is a lack of awareness and understanding of ethical issues. Therefore, it is essential to support the learning and development of ethical competencies among health care professionals.

In the area of Education, NH Ethics Service strives to:

 provide practice-oriented education and resources to support ethical practice and enhance ethics-related skills at all levels of the organization.

Practice-oriented education aims to develop ethical competencies such as being able to identify ethical dilemmas in health care, being familiar with fundamental principles of moral reasoning,

<sup>&</sup>lt;sup>3</sup> NH REB can be contacted at Research@northernhealth.ca.



and being able to reflect on one's own values and beliefs. It is geared towards even experienced professionals as developing ethical competences is a life-long commitment.

To provide practice-oriented education, NH Ethics Services works in conjunction with department managers and supervisors to determine the training needs of employees and organize tailored-made seminars and educational programs<sup>4</sup>.

## 4. Ethical Approaches Adopted by NH

Decisions about morality must be grounded in a reasoned approach to determine right and wrong. Ethical theories uncover the foundations of morality and represent the viewpoints from which individuals seek guidance as they make decisions.

Based on the recognition that there is a plurality of fundamentally morally good things, that not a single philosophical approach will always provide all the answers and that all theoretical approaches regardless of the considerations, decision-making styles, or ethical principles they emphasize are worthy of respect, NH has decided to draw on multiple recognized approaches to support ethical reasoning. In other words, **NH** has adopted a pluralistic approach to Ethics.

Ethical pluralism is well suited to the goals of social justice, anti-racism, cultural safety, justice, equity, diversity, and inclusion because it provides a flexible and dynamic theoretical framework from which the cultural, linguistic and moral context of different individuals can be understood and communicated. This way, ethical pluralism opens the door for the creation of ethical spaces in which mutual understanding is facilitated (21).

Approaching an ethically challenging situation from a plural standpoint requires to consider the various morally relevant factors, weigh which ones are most pressing and use those considerations to reason about what ought to be done. Several ethical theories provide important insights into the factors that are morally relevant in health care. Specifically, those theories are Ethics of Care, Narrative Ethics, Intersectional Bioethics, Rights-based Approaches, Principles of Biomedical Ethics and Rural Care Ethics.

Ethics of Care, also described as Relational Ethics, see individuals embedded in a series of relationships. It argues that moral knowledge can emanate from attending to those complex networks of relationships, from sensing and interpreting the needs and interests of those involved, and from identifying how to respond appropriately to their needs and interests (22).

Ethics of Care highlights how critical it is for health care providers to be sensitive to patients' and families' needs, concerns, and values and to facilitate ways to understand, nurture, and support these relationships (23). It also challenges traditional understandings of autonomy, competence,

<sup>&</sup>lt;sup>4</sup> To request the implementation of educational activities, staff members can contact the ethicist at Ethics@northernhealth.ca.



-

and quality of life highlighting the need to become more sensitive to the background circumstances that affect people's choices (22, 23).

Narrative Ethics recognizes the importance of narratives, those "stories people tell about their lives" (24, p30), to understand the various moral considerations that are relevant to a given situation. This approach encourages people to reflect on how their health care journey has unfolded. The perspectives, context and values revealed through the telling of the story are used to identify together the most appropriate care plan (25, 26). As the patient is recognised as the author of their own life-story, the power is shifted from health care providers back to patients and their families (26 - 30). Therefore, this approach enriches health care practice by making the analysis of an ethically challenging situation more attentive to the unique characteristics of the patient (31).

Intersectional bioethics emphasizes how the convergence of multiple social dimensions such as race, sex, gender, or class shapes actual lived experiences (32) and contributes to the unique forms of oppression and systemic barriers experienced by those with marginalized and intersecting identities (e.g., a black, disabled, transgender, woman). These considerations are especially relevant in health care where intersectionalities can play a major and even unconscious role in health care providers' judgments and actions (33). Therefore, by revealing the subtle ways in which intersectionalities shape people's lives and stressing the need for self-reflection, this approach constitutes a powerful tool for examining and addressing the oppressive vectors impacting the medical encounter (34, 35).

Rights-based ethics focuses on the rights and fundamental freedoms that are inherent to all human beings, without discrimination. It recognizes the existence of an indivisible relationship between the right to health care and the socio-economic factors (e.g., access to adequate supply of safe food, housing, safe and potable water, adequate sanitation, safe occupational and environmental conditions) that impact health (36). Therefore, a human rights approach to health provides a normative framework for pro-active development of policies and programs able to address health inequalities.

Principlism is a normative ethical framework that identifies widely acceptable *prima facie* principles whose relative priority is weighed in each situation (37). Within this approach, particular prominence is given to four principles: beneficence, non-maleficence, respect for autonomy and justice. In addition, NH also upholds the principles of compassion, equity, stewardship, confidentiality and truth-telling (see Appendix 11 for a definition of these values).

NH Ethics Service recognizes that there are other distinctive sources of moral wisdom in addition to Western moral philosophies. Specifically, NH strives to create an ethical space in which Indigenous and Western ways of knowledge can be brought into conversation to support Indigenous people to articulate their position and advance their knowledge claims. This aim is aligned with the recommendations of the Truth and Reconciliation Commission of Canada, which calls for physicians to "recognize the value of Aboriginal healing practices and use them in the



treatment of Aboriginal patients in collaboration with Aboriginal healers and Elders where requested by Aboriginal patients." (38, pp 210).

Rural Health Care Ethics is the overarching theoretical perspective that qualifies the application of all the above-mentioned approaches. Rural Health Care Ethics emphasizes how the unique characteristics of the rural environment - geographic isolation, enhanced familiarity due to close-knit relationships in small communities, lack of resources, stress from excessive demand, and cultural mores - shape moral challenges as well as health care providers' ability to respond to them (39). Therefore, to understand and address ethical dilemmas in rural and remote communities, it is important to recognise the context in which they arise and how that context influences the expression of moral values and, ultimately, ethical reasoning (39).

## 5. Promoting and Embedding Reconciliation in Health Care: the NH Approach

Canada's colonial history and its policies of cultural genocide and assimilation of Indigenous people have led to the introduction of systemic barriers and health inequities. Healthcare organizations have a critical role to play in helping to address this troubling health gap.

NH Ethics Service commits to:

- uphold Indigenous rights (40, 41), and promoting Indigenous cultural safety and humility; truth telling and reconciliation (42-44).
- promote anti-racism, cultural safety, justice, equity, diversity and inclusion.
- engage in purposeful, ongoing and inclusive partnerships with First Nations, Métis and Inuit.

Reconciliation and truth-telling is the avenue identified by the Truth and Reconciliation Commission (42) to repair the damaged relationship that exists between Indigenous and non-Indigenous peoples in Canada. Although different interpretations have been given to these terms, generally, they refer to acknowledging Canada's true history, establishing, and maintaining respectful relationships with Indigenous people and recognizing their inherent rights.

Indigenous rights are protected by the United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP) (40) and by the Declaration on the Rights of Indigenous Peoples Act (DRIPA) (41). UNDRIP is an international instrument that enshrines the rights that "constitute the minimum standards for the survival, dignity and well-being of the indigenous peoples of the world". It was put into law by BC in 2019 through the DRIPA. Both documents recognize the indigenous right to health and to access to health services without discrimination, which compels us to address the institutional factors that lead to health inequities at NH.

There are several determinants of health inequities. One of them is institutionalised racism. There are no doubts that racism against Indigenous people exists in Canadian healthcare as it has been evidenced by several studies (45-47) and public denunciations. There are also no doubts



that the racism experienced by Indigenous people seeking health care services must be eradicated.

NH Ethics Service commits to promote anti-racism, cultural safety, justice, equity, diversity, and inclusion. Specifically, these notions are integrated in the decision-making guidelines. In addition, NH Ethics Services supports anti-racism and cultural safety education as well as safe processes for both employees and clients to debrief racist or culturally unsafe experiences in the organization.

Cultural safety can be defined as, "an outcome that is based on respectful engagement which recognizes and strives to address power imbalances inherent in the health and social services system" (48). It requires health care professionals to acknowledge and address their own biases, attitudes, assumptions, and prejudices and the potential impact of their own culture on health care service delivery. It also requires organizations to examine their structures, policies, and operations as they may be affecting the quality of care provided. Adopting a comprehensive approach to cultural safety supports the creation of a health care environment free of racism and discrimination, and, therefore, safe, which in turn leads to the elimination of Indigenous health inequities.

Cultural safety needs to be understood alongside trauma-informed care, or care that is sensitive to how a person's lived experiences can impact their behaviours and health status. A trauma-informed organization realizes the widespread impact of trauma and creates potential paths for healing by integrating this knowledge into policies, procedures, and practices (49).

Another important determinant of health inequity is the exclusion of Indigenous people from discussions related to how health services should be organized and provided. That is why, NH Ethics Service commits to engage in purposeful, ongoing, and inclusive partnerships with First Nations, Metis and Inuit. These partnerships include learning from and working with traditional knowledge keepers, and Indigenous experts to ensure that Wise Practices are built upon to further improve the Canadian healthcare system.

Wise Practices are defined as "as locally-appropriate actions, tools, principles or decisions that contribute significantly to the development of sustainable and equitable social conditions" (50, 51) by highlighting the strengths of Indigenous ways of knowing and supporting Indigenous people access to traditional medicine, ceremony, and foods.

#### 6. Conclusions

NH Ethics Service is compromised of four C.O.R.E areas each with specific purposes. The work in these areas of service is informed by strong theoretical underpinnings, methodologically sound decision-making models and a firm commitment to promote Indigenous health and social equity. Those are the pillars that make of NH an ethically strong organization.



#### 7. References

- 1. Jiwani, B. (2017). Clinical ethics consultation: a practical guide. Springer.
- 2. Ellen Fox, "Concepts in Evaluation Applied to Ethics Consultation Research," Journal of Clinical Ethics 7.2 (1996): 116–121.
- 3. Thanh N. Huynh et al., "The Frequency and Cost of Treatment Perceived to Be Futile in Critical Care," JAMA Internal Medicine 173.20 (November 11, 2013): 1887–1894, doi: 10.1001/jamainternmed.2013.10261.
- 4. Thanh N. Huynh et al., "The Opportunity Cost of Futile Treatment in the ICU," Critical Care Medicine 42.9 (September 2014): 1977–1982, doi: 10.1097/CCM.0000000000000402.
- 5. Jessica Richmond Moeller et al., "Functions and Outcomes of a Clinical Medical Ethics Committee: A Review of 100 Consults," HEC Forum 24.2 (June 2012): 99–114, doi:10.1007/s10730-011-9170-9.
- 6. Elizabeth G. Nilson et al., "Clinical Ethics and the Quality Initiative: A Pilot Study for the Empirical Evaluation of Ethics Case Consultation," American Journal of Medical Quality 23.5 (October 2008): 356–364, doi: 10.1177/1062860608316729.
- 7. Douglas J. Opel et al., "Integrating Ethics and Patient Safety: The Role of Clinical Ethics Consultants in Quality Improvement," Journal of Clinical Ethics 20.3 (Fall 2009): 220–226.
- 8. Carrie A. Bennett, "A Place for Palliative Care," American Journal of Nursing 110.4 (April 2010): 72, doi: 10.1097/01.NAJ.0000370163.84802.8d.
- 9. Richard Brumley et al., "Increased Satisfaction with Care and Lower Costs: Results of a Randomized Trial of in-Home Palliative Care," Journal of the American Geriatrics Society 55.7 (July 2007): 993–1000, doi:10.1111/j.1532-5415.2007.01234.x.
- 10. Ross M. Hays et al., "The Seattle Pediatric Palliative Care Project: Effects on Family Satisfaction and Health-Related Quality of Life," Journal of Palliative Medicine 9.3 (June 2006): 716–728, https://doi.org/10.1089/jpm.2006.9.716.
- 11. Irene J. Higginson et al., "Do Hospital-Based Palliative Teams Improve Care for Patients or Families at the End of Life?," Journal of Pain and Symptom Management 23.2 (February 2002): 96–106.
- 12. Homan, Mary E. (2018). Factors Associated with the Timing and Patient Outcomes of Clinical Ethics Consultation in a Catholic Health Care System. \_The National Catholic Bioethics Quarterly 18 (1):71-92.
- 13. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. Tri-Agency Framework: Responsible Conduct of Research (2016). Retrieved on January 18, 2021, from <a href="https://rcr.ethics.gc.ca/eng/framework-cadre.html">https://rcr.ethics.gc.ca/eng/framework-cadre.html</a>.
- 14. Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans TCPS 2 (2018). Retrieved on January 18, 2021, from https://rcr.ethics.gc.ca/eng/framework-cadre.html.



- 15. Health Canada. Canada's Food and Drugs Act and Regulations. Retrieved on January 18, 2021, from https://www.canada.ca/en/health-canada/services/food-nutrition/legislation-guidelines/acts-regulations/canada-food-drugs.html.
- 16. Government of Canada. Canadian Charter of Rights and Freedoms, Constitution Act, 1982, Part 1 of Schedule B to the Canada Act (1982).
- 17. Personal Information Protection and Electronic Documents Act, S.C.2000, c.5, (2006). Date accessed 21 january 2021. <a href="http://laws-lois.justice.gc.ca/PDF/P-8.6.pdf">http://laws-lois.justice.gc.ca/PDF/P-8.6.pdf</a>
- 18. Privacy Act, R.S. 1985, c.P-21, Privacy Act, R.S. 1985, c.P-21, (2006).
- 19. Personal Information Protection Act. Government of BC. Available: <u>Personal Information Protection Act Province of British Columbia (gov.bc.ca)</u>
- 20. CIHR Best Practices for Protecting Privacy in health Resarch (September 2005). https://cihr-irsc.gc.ca/e/29072.html. Accessed January 24 2021
- 21. Niebroj L. Bioethics of life programs: taking seriously moral pluralism in clinical settings. Eur J Med Res. 2010 Nov 4;15 Suppl 2(Suppl 2):98-101. doi: 10.1186/2047-783x-15-s2-98. PMID: 21147632; PMCID: PMC4360374.
- 22. Noddings, N. (2012). The language of care ethics. Knowledge Quest, 40(5), 52-56.
- 23. Storch, J. L., Rodney, P., & Starzomski, R. C. (2013). *Toward a moral horizon: Nursing ethics for leadership and practice.* Toronto: Pearson.
- 24. Bochner, A. P. (1994). Perspectives on inquiry II: Theories and stories. In M. L. Knapp & G. R. Miller (Eds.), Handbook of Interpersonal communication (pp. 21–41). Thousand Oaks, CA: Sage. (page 30)
- 25. Montello, M. (2014). Narrative ethics. Hastings Center Report, 44(1), S2-S6.
- 26. Brody, H., & Clark, M. (2014). Narrative ethics: A Narrative. Hastings Center Report, 44(1), S7-S11.
- 27. Brody H. Stories of sickness. New Haven: Yale University Press, 1987.
- 28. Brody H. "My story is broken; can you help me fix it?" Medical ethics and the joint construction of narrative. Lit Med 1994; 13: 79-92.
- 29. Churchill LR. The human experience of dying: the moral primacy of stories over stages. Soundings 1979; 62: 24-37.
- 30. Jones AH. From principles to reflective practice or narrative ethics? In: Carson RA, Burns CR, eds. Philosophy of medicine and bioethics: a twenty-year retrospective and critical appraisal. Dordrecht: Kluwer Academic Publishers, 1997: 193-95.
- 31. Charon R. Narrative contributions to medical ethics: recognition, formulation, interpretation, and validation in the practice of the ethicist. In: DuBose ER, Hamel RP, O'Connell LJ, eds. A matter of principles? Ferment in U. S. bioethics. Valley Forge: Trinity Press International, 1994: 260-83.
- 32. Crenshaw, K. W. 1989. Demarginalizing the intersection of race and sex: A black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. University of Chicago Legal Forum 1989 (1):139–67.
- 33. Salloch, S., I. Otte, A. Reinacher-Schick, and J. Vollmann. 2018. What does physicians' clinical expertise contribute to oncologic decision-making? A qualitative interview study. Journal of Evaluation in Clinical Practice 24 (1): 180–6. doi: 10.1111/jep.12840.



- 34. Wilson, Y., White, A., Jefferson, A., & Danis, M. (2019). Intersectionality in clinical medicine: The need for a conceptual framework. *The American Journal of Bioethics*, 19(2), 8–19. https://doi.org/10.1080/15265161.2018.1557275
- 35. Grzanka, P. R., Brian, J. D., & Shim, J. K. (2016). My bioethics will be intersectional or it will be [bleep]. *The American Journal of Bioethics*, *16*(4), 27–29. https://doi.org/10.1080/15265161.2016.1145289
- 36. Beracochea, Weinstein, C., & Evans, D. P. (2011). *Rights-based approaches to public health*. Springer Pub. Co.
- 37. Beauchamp, T. L., and J. F. Childress. 2013. Principles of Biomedical Ethics. 7th ed. New York:Oxford University Press.
- 38. Truth and Reconciliation Commission of Canada. (2015). *Truth and Reconciliation Commission of Canada: Calls to action*. https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls to action english2.pdf
- 39. Simpson, Christy; McDonald, Fiona. Rethinking Rural Health Ethics. Springer Publishing Inc. 2017.
- 40. United Nations. (2007). *United Nations Declaration on the Rights of Indigenous People.* https://www.un.org/development/desa/indigenouspeoples/declaration-on-the-rights-of-indigenous-peoples.html
- 41. Declaration on the Rights of Indigenous Peoples Act. (2019). BC Laws. https://www.bclaws.gov.bc.ca/civix/document/id/complete/statreg/19044
- 42. Truth and Reconciliation Commission of Canada. (2015). *Truth and Reconciliation Commission of Canada: Calls to action*. https://www2.gov.bc.ca/assets/gov/british-columbians-our-governments/indigenous-people/aboriginal-peoples-documents/calls\_to\_action\_english2.pdf
- 43. National Inquiry into Missing and Murdered Indigenous Women and Girls. (2019) Reclaiming power and place: The final report of the National Inquiry into Missing and Murdered Indigenous Women and Girls. https://www.mmiwg-ffada.ca/final-report/
- 44. Turpel-Lafond, M. E. (2020). *In plain sight: Addressing Indigenous-specific racism and discrimination in B.C. health care (data report)*. <a href="https://engage.gov.bc.ca/app/uploads/sites/613/2021/02/In-Plain-Sight-Data-Report Dec2020.pdf1.pdf">https://engage.gov.bc.ca/app/uploads/sites/613/2021/02/In-Plain-Sight-Data-Report Dec2020.pdf1.pdf</a>
- 45. HealthCareCAN, Canadian College of Health Leaders (2017) Media Release: Discrimination common while providing health care for Indigenous Canadians. Available: http://www.nhlc-cnls.ca/wp-content/uploads/2017/06/IpsosPoll\_IndigenousHealth\_Release.pdf
- 46. Browne AJ et.al. (2016) Enhancing health care equity with Indigenous populations: evidence-based strategies from an ethnographic study. BMC Health Services Research. 16:544. Available: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5050637/
- 47. The College of Family Physicians of Canada (2016) Health and Health Care Implications of Systemic Racism on Indigenous Peoples in Canada. Available: <a href="http://www.cfpc.ca/uploadedFiles/Resources/">http://www.cfpc.ca/uploadedFiles/Resources/</a> PDFs/SystemicRacism ENG.pdf
- 48. First Nation Health Authority of BC (2016) Creating a Climate for Change Cultural Safety and Humility in Health Services for First Nations and Aboriginal Peoples in British



- Columbia. Page 5. Available: <a href="http://www.fnha.ca/documents/fnha-creating-a-climate-for-change-cultural-humility-resource-booklet.pdf">http://www.fnha.ca/documents/fnha-creating-a-climate-for-change-cultural-humility-resource-booklet.pdf</a>
- 49. Klinic Community Health Centre (2013) Trauma-informed: The Trauma Toolkit. Second edition. Available: <a href="http://trauma-informed.ca/wp-content/uploads/2013/10/Trauma-informed">http://trauma-informed.ca/wp-content/uploads/2013/10/Trauma-informed</a> Toolkit.pdf
- 50. Wesley-Esquimaux, Cynthia and Brian Calliou, (2010) "Best Practices in Aboriginal Community Development: A Literature review and Wise Practices Approach." Available: <a href="https://communities4families.ca/wp-content/uploads/2014/08/Aboriginal-Community-Development.pdf">https://communities4families.ca/wp-content/uploads/2014/08/Aboriginal-Community-Development.pdf</a>
- 51. Churchill M et al. (2017) Evidence Brief: Wise Practices for Indigenous-specific Cultural Safety Training Programs. Available: <a href="http://www.welllivinghouse.com/wp-content/uploads/2019/05/2017-Wise-Practices-in-Indigenous-Specific-Cultural-Safety-Training-Programs.pdf">http://www.welllivinghouse.com/wp-content/uploads/2019/05/2017-Wise-Practices-in-Indigenous-Specific-Cultural-Safety-Training-Programs.pdf</a>



#### 8. Appendixes

## Appendix 1 - Northern Health Authority Ethics Committee, Terms of Reference

#### 1. PURPOSE:

The purpose of NH Ethics Committees is to support NH vision of "leading the way in promoting health and providing health services for Northern and rural populations" by fulfilling our mission of "cultivating a culture and practice of Ethics as the foundation for all NH activities".

#### 2. RESPONSIBILITIES:

The Northern Health Ethics Committee provides leadership and guidance to the HSDA Ethics Committees, the Ethicist and the Board regarding:

- ethics case consultations that could not be resolved by the NH HSDA Ethics Committees,
- standardization of processes within the overall ethics committee structure,
- creation and interpretation of policies, guidelines, directives and frameworks,
- further the level of knowledge and understanding of ethics and ethical issues through initiation of, participation in, and support of educational endeavors,
- scan the wider ethical community and share information within Northern Health and liaise/network with other ethics bodies provincially and nationally.
- develop an ethics Communications Plan.

#### 3. AUTHORITY:

The Northern Health Ethics Committee functions under the authority of the Northern Health Board. (See organizational diagram – Appendix 4).

#### 4. MEMBERSHIP AND TERM:

NH Ethics Services will foster diversity, equity, and inclusion including collaborating with Indigenous Health and other Stakeholders to maintain a multi-disciplinary and diverse Committee membership.

When considering overall committee composition, and when selecting members to fill vacancies, attention should be given to ensure that the committee: is multidisciplinary with no one discipline having a majority of the members; has wide geographical representation; is gender balanced; and have at least one person who is a community representative who is not employed by Northern Health. Attempts should be made to have ethnic diversity that reflects the community. Membership may include individuals active or retired from medicine, nursing, pastoral care, administration and the legal system. It is strongly recommended that there be at least one physician on the committee. Members must have the ability to do ethical reflection and show a commitment and interest in ethical practice.

Some members may be appointed to ensure the membership goals are met. Patients/clients/residents, family and community members should not be employed by NH.



Staff members attending during work hours must have permission of their manager to participate.

Active minimum core membership should consist of:

- The Co-Chair and one member from each of the three HSDA Ethics Sub-Committees (6)
- Up to four members at large with knowledge and acumen in ethics may be appointed by the NH Committee from the community, NH employees or medical staff to support the duties of the committee (1-4)
- Risk Management (1)
- NH Executive Committee (1)
- Ex officio: Chief Medical Health Officer and VP Medicine (2)

#### 5. LOGISTICS:

- 5.1 Term: Members, excluding the Ethicist, are appointed for a 3-year term, unless on the committee by virtue of their position/role in the organization. Efforts should be made to stagger terms. There is no term limit.
- 5.2 Co-Chairs: The NH Ethicist, and (1) non-NH Ethicist Committee member will be appointed as Co-chairs. Every 2 years, or earlier in the case of a vacancy, all Committee members will have an opportunity to put their name forth or nominate another committee member for the non-NH Ethicist Co-chair position, including the incumbent non-NH Ethicist Co-chair. In the event that the Ethicist position is vacant, the non-Ethicist will assume full responsibility for chairing the committee.
- 5.3 Secretary: The committee will be provided an administrative support by NH or HSDA administration for record keeping and for coordinating the logistics of meetings.
- 5.4 Meetings: Meetings will be held at a minimum of three times per year and at the call of the Co-Chairs.
- 5.5 Quorum: NH A meeting quorum will be at least 5 members with at least one member from each HSDA committee present. A voting quorum will be a simple majority of the members present. Failure to attend regularly may constitute a resignation and a replacement may be requested.
- 5.6 Records: Record keeping will be in the form of minutes of discussions. Reference to particular patients/residents will be anonymous. All documents will be housed on an iPortal site accessible by all committee members.

In the event of dissolution of the NH Ethics Committee, all records shall remain the property of Northern Health.



## **6. CONFIDENTIALITY:**

All members of Northern Health Ethics Committees shall be required to review and reaffirm compliance with NH policies regarding confidentiality. Committee members who are not employed by Northern Health shall review, sign and abide with the policies of Northern Health prior to commencement of their committee membership.

#### 7. REPORTING:

Northern Health Ethics Committee Co-Chairs will provide a report to the Executive Committee of Northern Health and to the Northern Health Medical Advisory Committee (NHMAC) at request. The Northern Health Ethics committee will provide a written annual report to the Performance, Planning and Priorities (3P) Committee of the Board, in accordance with the 3P Committee work plan.

#### 8. REVIEW OF TERMS OF REFERENCE:

Terms of Reference will be reviewed at least every three years.

#### Reference:

Manitoba Provincial Health Ethics Network, *Health Ethics Committee Toolkit, Part One: Getting Started*, 2011, <a href="http://www.mb-phen.ca/files/ToolkitforEthicsCommitteesPart1-">http://www.mb-phen.ca/files/ToolkitforEthicsCommitteesPart1-</a>
AdaptedFebruary2011.pdf



## Appendix 2 - Northern Health Authority HSDA Ethics Committees, Terms of Reference

The purpose of NH HSDA Ethics Committees (NE, NW and NI Committees) is to support NH vision of "leading the way in promoting health and providing health services for Northern and rural populations" by fulfilling our mission of "cultivating a culture and practice of Ethics as the foundation for all NH activities".

#### 1. RESPONSIBILITIES

As deemed appropriate by the NH Ethicist(s), NH HSDA Ethics Committees will be consulted in the following areas:

- Case Consultations
  - Working with the NH Ethicist, provide consultative service with ethics-based analysis and recommendations to assist the parties involved in situations related to ethical issues in health care.
- Policy/Guidelines
  - Review and interpret NH policies/guidelines/frameworks from an ethical perspective.
  - Direct recommendations and issues with region-wide implications to the NH Ethics committee.
- Quality Assurance
  - Provide ongoing quality assurance measures to strengthen NH Ethics Services, including peer review of some of the Ethicists' consultations and make recommendations about the sustainability and resource requirements of NH Ethics Services.
- Education
  - o In collaboration with the Ethicist, provides education and support to health care providers, clients, and families in partnership with the community at large.

#### 3. AUTHORITY

NH HSDA Ethics Committees (NW, NE, NI) function as sub-committees of the NH Ethics Committee, and within the context of NH Policy.

#### 4. MEMBERSHIP AND TERM:

NH Ethics Services will foster diversity, equity, and inclusion including collaborating with Indigenous Health and other stakeholders to maintain a multi-disciplinary and diverse committee membership.

When considering overall committee composition, and when selecting members to fill vacancies, attention should be given to ensure that the committee: is multidisciplinary with no one discipline having a majority of the members; has wide geographical representation; is gender balanced; and have at least one person who is a community representative who is not employed by Northern Health. Attempts should be made to have ethnic diversity that reflects the community. Membership may include individuals active or retired from medicine, nursing,



pastoral care, administration and the legal system. It is strongly recommended that there be at least one physician on the committee. Members must have the ability to do ethical reflection and show a commitment and interest in ethical practice.

Some members may be appointed to ensure the membership goals are met. Patients/clients/residents, family and community members should not be employed by NH.

Staff members attending during work hours must have permission of their manager to participate.

Active minimum core membership should consist of:

- 1 Physician
- 1 Nurse Practitioner
- 1 Nurse
- 1 Allied Health
- 1 Community member
- Ex Officio: HSDA, Medical Director, Chief Operating Officer

#### 5. LOGISTICS:

- **5.1 Term:** Term, excluding the Ethicist(s), will be a minimum of 2 years with additional terms allowed to a maximum of 6 years, subject to the goals of membership being met. Membership terms will be managed to ensure a balance of experienced and new members.
- **5.2 Members**: Annual review of membership by the committee with new members ideally committing for four years. The Committee will strive for a good mix between new and existing members.

The composition of the committee may allow for members to be nominated by particular HSDAs or self-nominated, or to serve ex officio.

**Elected members** will be nominated initially by the specified HSDA COO because of their expertise in specific areas or because they clearly represent particular groups. They can also be self-nominated. If there are more nominations than vacancies a secret election is held in which all members of the Committee may vote.

**Nominated members** are identified by the HSDA COO.

**Self-nominated members** can contact the Co-Chairs expressing their interest in the Committee's membership.

**Ex officio members** are members by virtue of their role at NHA.

Members must demonstrate a commitment to be active participants in the meetings and consultations as well as to participate in ongoing education in the field of ethics.



Subcommittees or work groups may be established to perform functions of the Committee in areas such as Education, and Consultation.

#### 5.3 Co-Chairs:

The NH Ethicist, and (1) non-NH Ethicist Committee member will be appointed as Co-chairs. Every 2 years, or earlier in the case of a vacancy, all Committee members will have an opportunity to put their name forth or nominate another committee member for the non-NH Ethicist Co-chair position, including the incumbent non-NH Ethicist Co-chair. In the event that the Ethicist position is vacant, the non-Ethicist will assume full responsibility for chairing the committee.

- **5.4 Administrative support** will be provided by the HSDA.
- **5.5 Meetings** will be held a minimum of 4 times per year, or at the call of the Co-Chairs as needed. Meetings will be by teleconference / videoconference.

Ad hoc meetings may be called for urgent case consultations and/or other matters requiring Committee input (e.g., policy review). It is recognized that members may not be able to attend ad hoc meetings due to other commitments but attendance is highly encouraged.

If a member can't attend a meeting, they should notify the Ethicist Co-chair in advance and arrange to provide comments on agenda items.

Other expectations of Committee Members:

- Review case consultation write-ups, policies and other documents and provide feedback, as requested.
- Within the first year of becoming a member, attend a NH Ethics Orientation Workshop, complete the on-line HUB Learning Ethics Modules (if not already completed).
- Support the Ethics Education Sessions, as needed, and attend as many education sessions as feasible.
- **5.6 Quorum:** Each member will be required to attend at least two-thirds of the regularly scheduled meetings each year. Failure to attend may constitute a resignation and a membership replacement. Quorum will be the minimum core membership as noted.
- **5.7 Records of the Committee:** Records of the committee will be kept by the local HSDA. Upon dissolution of the committee, the records will be given to the NHA Ethicist for appropriate storage or disposal.

## 6. Process & Upholding NH Values

Meetings will be conducted using principles of openness, transparency and consensus building where all members have input into discussions and Committee outcomes. NH values (empathy, respect, collaboration and innovation) will be respected and promoted.



## **6.1 Dispute Resolution**

Where disagreements arise, all parties are expected to, in good faith, use their best efforts to consider opposing views and attempt to come to a consensus or other mutually agreeable resolution. In the event that a disagreement cannot be directly resolved between parties, the stepwise process for dispute resolution will be as follows:

Step 1 – The disputing individuals or group(s) will provide notice to all disputing parties and present its (their) position, with reasons, to the NH Ethics Committee which will assess the issue and attempt to resolve the dispute to the satisfaction of the disagreeing parties.

Step 2 – If the NH Ethics Committee is unable to resolve the issue, the matter will be referred to the Regional Director, Legal Affairs, Enterprise Risk & Compliance, who will attempt to mediate a resolution.

Step 3 – If a mediated resolution cannot be achieved, the Regional Director, Legal Affairs, Enterprise Risk & Compliance will make the final binding decision.

Any resolutions achieved using the process outlined above will not be considered precedent setting.

#### 7. CONFIDENTIALITY:

Members of the NH HSDA Ethics Committees will be required to have signed a confidentiality agreement with NH.

Members should also notify the Ethicist Co-chair in advance if there is a potential personal or professional conflict of interest.

#### 8. REPORTING:

Minutes of the NH HSDA Ethics Committees will be sent (within 10 business days of meeting) to NH Ethics Committee and to the members of the regional committee involved in the meeting.

Minutes / Reports should not contain information that could identify individual patients, family members, clients, volunteers etc. or situations.

Annual Report on highlights of Committee activities will be sent to NH Ethics Committee, all regional committees, the corresponding executive teams and the Board of Directors.

The Committees will review the annual report and consider any recommendations regarding the sustainability of Ethics Services including resources, independence or any other measures required to achieve the mission of Ethics Services.



At least once a year, Committee members will also be surveyed to gather input on quality improvement measures to advance the ability to meet the Committee's "Purpose" as stated above.

## 9. REVIEW OF TERMS OF REFERENCE:

The terms of reference will be reviewed annually.



## Appendix 3 – Northern Health Research Ethics Board, Terms of Reference

#### 1. Purpose

- Northern Health (NH) Research Ethics Board (REB) is mandated to approve, reject, propose modifications to, or terminate any proposed or ongoing research involving humans conducted in NH facilities/programs.
- NH REB's function is to ensure that ethical principles and standards respecting the personal welfare and rights of research participants have been recognized and accommodated.
- NH REB follows, the BC Freedom of Information and Protection of Privacy Act (FIPPA)
  and the Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans
  (TCPS2) (https://ethics.gc.ca/eng/policy-politique\_tcps2-eptc2\_2018.html) and related
  policies.

## 2. Accountability

- NH REB is accountable to the Governance and Management Relations (GMR) Committee of the NH Board through the Executive Sponsor (Vice President, Planning, Quality and Information Management).
- The Executive sponsor or their delegate Regional Director, Research, Evaluation and Analytics may sub-delegate duties listed below to the Lead, Clinician & Research Ethics but remain responsible for providing the financial and administrative resources that are necessary to enable NH REB to fulfil its duties and remain answerable to the GMR Committee of the Board on such duties.
- An annual report will be submitted by the NH REB Chair to the Executive sponsor who will bring it forward to the GMR Committee of the Board.

## 3. Membership

In accordance with the TCPS2 (1), NH REB will consist of at least five members, of whom:

- At least two members have expertise in relevant research disciplines, fields and methodologies covered by NH REB (e.g., relevant health sciences, qualitative and quantitative methods);
- At least one member is knowledgeable in ethics;



- At least one member is knowledgeable in the relevant law<sup>5</sup>; and
- At least one community member who has no other affiliation with NH.

#### In addition:

- Membership should represent the diversity of the communities and geographical regions served by NH. Every effort will be made to include cultural and ethnic minorities to represent the population from which research participants are recruited, within the scope of available expertise needed to conduct NH REB functions.
- Membership should reflect NH's commitment to developing, promoting, and implementing diversity, inclusion, and equity.
- Equal consideration shall be given to qualified persons of all gender identities. No appointment shall be made solely on the basis of gender identities.
- Medical staff representation: one member from the faculty of the University of British Columbia Northern Medical Program and/or one privileged medical staff member recommended by the Medical Advisory Committee
- One member of the NH Privacy Office.
- The Chair, in consultation with the Co-Chair as well as with the Executive sponsor, its Delegate or sub-delegate, will establish and maintain a roster of Associate NH REB members. The function of an Associate member is to review applications that meet the criteria of being "minimal risk" and fall within their area of expertise (e.g., clinical practice or business area, research methodology expertise).
- Associate members may be required to provide input on applications that meet the criteria of being "higher than minimal risk" and fall within their area of expertise.
- Associate members will conduct reviews to support NH REB mandate but will not meet with the full NH REB during regularly scheduled monthly meetings and won't vote on decisions if the study is higher than minimal risk.
- The term of appointment for Associate members is not limited.

#### 4. Appointment

- The Executive sponsor in consultation with their delegates or sub-delegates as well as with the NH REB Chair may appoint NH REB membership based on experience with research, expertise and needs of the NH REB.
- Appointments shall be for a two-year term. Terms will overlap for the purposes of continuity and may be renewed. There is no limit on reappointments.

<sup>&</sup>lt;sup>5</sup> The role of NH REB member knowledgeable in applicable law is to alert NH REB to legal issues and their implications, not to provide formal legal opinions nor to serve as legal counsel. This is mandatory for biomedical research and is advisable, but not mandatory, for other areas of research.



\_

- The Executive Sponsor in consultation with their Delegates or Sub-Delegates will review and appoint the Chair every two years. A Chair may serve for a maximum of two consecutive terms.
- Committee members will select a Co-Chair who will support the Chair by facilitating meetings and training opportunities. If the Chair is absent for a particular meeting, the Co-Chair will be responsible for leading and coordinating that meeting as needed. If the Chair is absent for more than two months, an interim Chair, who could or could not be the Co-Chair, could be appointed.

## 5. Support

- Administrative assistance shall be provided by the Planning, Quality and Information Management Team.

## 6. Meetings and Attendance

- Meetings are held monthly, except in the months of December, July or August, or at the discretion of the Chair. NH REB members shall meet face-to-face or via video or teleconference.
- Members are responsible to attend NH REB meetings. Members shall normally miss no more than two meetings per year. When unexpected circumstances arise that prevent a regular member from attending a meeting, the member will notify NH REB administrative support about the intended absence. If a regular member cannot attend NH REB meetings for a protracted period (e.g., 6 months leave), a substitute member may be appointed to serve during the regular member's absence.

#### 7. Quorum

- Quorum is 50% of NH REB membership

#### 8. Decision making

- NH REB will normally attempt to make decisions by consensus. If disagreement persists, majority vote will prevail with the NH REB Chair's vote serving as a tiebreaker. If quorum is not present at the meeting, a decision may be made with the NH REB membership via email vote, facilitated by the Chair.
- Members will declare any conflict of interest related to a study submitted for NH REB review. NH REB may decide that the member must withdraw from NH REB deliberations and decisions related to that study.
- NH REB members assigned to review a study will complete the Reviewer's Checklist prior to the meeting, culminating in a recommendation to:
  - Approve; if all requirements have been met satisfactorily
  - Not approve conditional; with questions and comments that require response by the researcher documented in the checklist
  - Not approve final; the application does not meet requirements and the researcher may resubmit to a future meeting.



- The NH REB will discuss the study application and make a decision that will be communicated to the researcher. The NH REB will work with researchers to resolve any perceived shortcomings in the research review application and protocol. The researcher has the right to request, and the NH REB has an obligation to provide, reconsideration of a decision affecting a research project.
- If an NH REB member or Associate NH REB member is unable to complete an assigned review they will notify NH REB Administrative support within two days of assignment so that the review can be reassigned to another NH REB member.

#### 9. Harmonized research ethics review

- Northern Health is a member of the network of REBs supported by Research Ethics BC as part of Michael Smith Health Research BC. Research Ethics BC supports the network of REBs in the BC harmonized ethics review process for multi-jurisdictional studies.
- NH REB may participate in harmonized ethics reviews of multi-jurisdictional research studies in collaboration with other health authorities, universities and colleges in BC.
- The harmonized research ethics review process will be governed by the provincial Guidance for Harmonized Multi-jurisdictional Studies with a designated Board of Record for each study that has the ultimate authority for the ethics review and oversight for the research project.
- Researchers involved in multi-jurisdictional research are required to apply for operational approval directly with NH.

## 10. Record keeping

- A numbered log will be kept of all research review applications.
- Minutes of all NH REB meetings shall be prepared and maintained by Administrative support of the Planning, Quality and Information Management Department.
- Records pertaining to the operations of the REB will be retained for 25 years. These records include meeting minutes, membership lists, Terms of Reference, member files, policies, and Standard Operating Procedures.
- Records will be stored electronically on the NH network in a secure drive and accessed by authorized NH REB members only, using a password.
- Paper records will be stored safely in NH offices in a locked cabinet.
- The minutes shall clearly document NH REB decisions as well as any dissents and the reasons for them. To assist internal and external audits or research monitoring, and to facilitate reconsideration or appeals, the minutes will be accessible to authorized representatives of NH.
- Researchers will be informed by e-mail or letter about the results of their application review, and NH staff who provided operational approval will be copied on distribution.



#### 11. Amendments

Changes to the Terms of Reference will not take effect until approved by the VP Planning,
 Quality and Information Management.

## 12. NH REB member responsibilities

- Complete the "TCPS 2: CORE-2022 (Course on Research Ethics)" at https://tcps2core.ca/welcome.
- Review assigned studies both minimal risk reviewed in between meetings, and greater than minimal risk reviewed during monthly meetings - and provide feedback prior to the date required and communicated in the request for review.
- The due date for review is determined by the next NH REB meeting date or within 10 business days of receipt of an application from the Board of Record for harmonized ethics reviews (as per the Guidance for Harmonized Ethics Review of Multi-Jurisdictional Studies). Reviews may include applications for initial ethical review, applications for amendment and renewal of previously approved studies, and responses to studies that have been deferred from a previous committee review.
- If unable to complete the review it is the responsibility of the committee member to inform NH REB Administrative support within two days of assignment so that the review can be reassigned to another committee member.
- Submit written comments on assigned studies to the NH REB office prior to the deadline for compilation into the correspondence with the NH REB Chair, the researcher or Board of Record as indicated in the request for review.
- Ensure that the study complies with the applicable Canadian Federal and Provincial and U.S. regulations when applicable and that all research complies with the current version of the Tri- Council Policy for Ethical Policy Statement: Ethical Conduct for Research Involving Humans (1) and other non-regulatory requirements.
- Make a decision about the outcome of the review for each study as follows:
  - o Approve; if all NH REB requirements have been met satisfactorily
  - Not approve conditional; with questions and comments that require response by the researcher documented in the checklist or email to NH REB office
  - Not approve final; the application does not meet requirements and the researcher may resubmit to a future meeting.
- If the member feels that the study should be reviewed by someone with a particular expertise, notify NH REB Chair.
- Support the development of guidance notes, policies and procedures for ethical review in collaboration with NH REB Chair, NH REB administrative support and when required by the Executive Sponsor.
- Participate in educational activities, evaluations, audits or investigations related to the oversight of research ethics at NH.



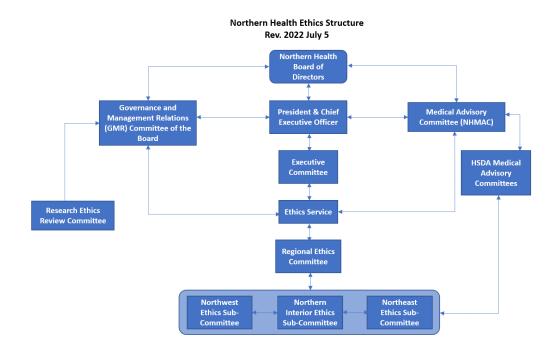
- Declare any conflict of interest pertaining to studies on the NH REB agenda before discussion begins.

## **REFERENCES**

1) Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, Social Sciences and Humanities Research Council of Canada. Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans – TCPS 2 (2018). Retrieved on January 18, 2021, from https://rcr.ethics.gc.ca/eng/framework-cadre.html.



# **Appendix 4 - NH Ethics Service Structure**





## **Appendix 5 - NH Method for Decision-Making in Clinical Ethics**

Making good ethical choices requires a trained moral sensitivity and a consistent decision-making process. NH Method for Decision-Making in Clinical Ethics aims to facilitate a careful, comprehensive exploration of ethical dilemmas that arise during the provision of medical care. Its value derives from being theoretically grounded and from putting into practice NH commitment to promote and embed reconciliation within organizational practices and operations.

Collaboration						1- Identify
Innovation			Background information			
Respect	<ul> <li>Summarize the ethical dilemma as it is experienced at this stage</li> <li>Identify the community of concern (individuals who should be involved in the decision-making process.)</li> </ul>					
Empathy						2- Consider
Medical Indications Patient journe		ent's preferences and health ney		Contextual Factors		HCPs personal values and beliefs
prognosis.  - Goals of treatment Proposed clinical interventions (nature, potential outcomes, benefits and harms) Potential impact on patient's quality of		- What is known about the patient's health journey (create a safe space for the patient to share their story, elicit their views, address their distress) Patient's preferences and values Patients decision-making ability (if needed, identify SDMs).		- Factors that may be influencing the situation e.g. professional, financial, resource allocation, legal, interpersonal, public health, confidentiality.		<ul> <li>Your personal position regarding the ethical issue.</li> <li>Assumptions and stereotypes about the patient and their culture.</li> <li>Power imbalances and privileges impacting the situation.</li> </ul>
lead to changes of treatment plan?  How can this patient be benefited  •		<ul> <li>Has the patient consented to the proposed intervention?</li> <li>Are the patient's views and right to choose being respected?</li> </ul>		Are contextual factors limiting the potential decision?		Has a culturally safe space been created?     If biases, prejudice, or discrimination are present, how will you address them?
						3- Analyze
Ethical Dilemma		Pote	ential courses of action		Decision's	moral acceptability
- State the ethical dilemma Identify relevant ethical values and other ethical considerations Rank them according to their importance in the current situation.		Identify all potential courses of action.     Determine how each option satisfies the ethical value that should take precedence.		- Determine whether the patient and the community of concern agree with the course of action identified Identify the factors that would have to change to alter the decision.		
Which value or consideration should take precedence?			Which course of action is most consistent with the value that should take precedence?		<ul><li> Has the patient been listened to?</li><li> Have harms been prevented?</li><li> Will this decision maintain trust?</li><li> Is the decision fair?</li></ul>	
						4- Implement
Implementing the decision			Documenting the decision			Evaluate the decision
<ul> <li>Identify the actions that need to be taken and the timeline.</li> <li>Identify who will be responsible for implementing them.</li> </ul>			- Identify who will be responsible for documentation Specify how the decision will be documented.		Looking back, is there something that could have been done differently?     What has the team learned?	



## Appendix 6 - NH Method for Decision-Making in Organizational Ethics

This guideline offers a structured process to make health care management decisions in situations of ethical choice. Its value resides in the depth and breadth of the considerations it prompts decision makers to reflect upon.

It consists of 6 steps represented sequentially. However, earlier steps may need to be revisited in light of responses to later ones. Additionally, depending on the issue under consideration, the questions grouped within a specific step may carry different relevance.



1- Identify Context	4- Evaluate the Decision Identified						
<ul> <li>What is the decision problem?</li> <li>What are its moral connotations?</li> <li>How does it relate to NH's strategic priorities?</li> <li>Is this the appropriate time to address the problem?</li> <li>Will you be able to decide fairly? If not, how will you address potential conflicts of interest?</li> <li>Who else should be involved in the decision-making process? To what extent? How?</li> </ul>	<ul> <li>Has all the information been justly and objectively evaluated?</li> <li>Is the decision identified in (3) evidence-based, feasible, sustainable and cost-effective?</li> <li>During the decision-making process did you remain free of biases?</li> <li>Would you feel comfortable defending your decision to others?</li> <li>Does the community of concern agree with the decision?</li> <li>Does the decision enables justice, diversity, equity and inclusion in health care?</li> <li>Does the decision uphold NH's values?</li> </ul>						
2- Consider the Available Information	5- Implement the Decision						
<ul><li>What is known about the issue?</li><li>Is the available data enough to make a decision?</li><li>Is the decision problem framed accurately?</li></ul>	<ul><li> How will the decision be implemented?</li><li> Who will be responsible for implementing it?</li></ul>						
3- Perform Ethical Analysis		6- Follow Up					
<ul> <li>What are the organizationally relevant ethical values the final decision must fulfill?</li> <li>How should those values be prioritized?</li> <li>What are the potential decisions?</li> <li>Which decision is most consistent with the value(s) that should take precedence?</li> </ul>	Retrospectively,  Have all parties followed through with the decision?  Was the community of concern properly informed?  Was the plan implemented in a timely manner?  Were there any unforeseen consequences?	Prospectively,  • Should the decision be revised in light of new information?  • What can be learned from the decision and its outcome?					

#### Organizational Decisions must Fulfill these Values

- Utilitarianism: It must produce the best overall result.
- Equity: It must ensure equity and protects the interests of vulnerable, or historically oppressed communities.
- Individuals' rights: It must respect individual rights (e.g., right to privacy, free speech, due process, autonomy etc.).
- Justice: It must remove barriers or burdens historically imposed on marginalized and oppressed individuals. Preservation of relationships: It must protect relationships among individuals and with health care institutions.
- Truth telling: Moral duty to be honest regarding why and how decisions have been made.
- Stewardship of resources: It must allocate resources effectively and efficiently. Therefore, it must consider:
- a) Population needs: Greater need justifies allocating more resources
- c) Equal treatment: Equal claims based on need and prognosis justify equal priority for resource allocation.
- b) Clinical prognosis: Greater expected health effect justifies allocating more resources
- d) Cost-effectiveness: Addressing a prioritised need should not spend more resources than necessary.
- Sustainability: Allocating a resource at a specific time should not compromise the ability of the organization to meet the same or other needs in the future.
- Social responsibility: The decision must ensure the organization fulfils its responsibility towards patients and communities.



Not all decision-makers follow a defined, prescriptive decision-making model like the one proposed here. Instead, they make decisions by judgement. In those situations, it is advisable to use the "Organizational Decision-Making – Ethical Considerations" (Appendix 7) to determine the quality and ethical acceptability of the decision after it is made and before it is implemented.



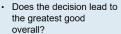
## Appendix 7 - Organizational Decision-Making - Ethical Considerations

Use this set of questions to assess the quality and ethical acceptability of your decisions before they are implemented. The questions summarize critical aspects that must be considered in order to make an ethical decision.

# NH Method for Decision-Making in **Organizational Ethics - Abridged**

- Are you free of conflict of interests?
- Are you free of preconceived ideas about the individuals, groups or situations involved?
- Are you fully considering all the evidence?
- Would you feel comfortable defending this decision to others?

**About your** 



- · Do benefits outweigh harms?
- · Does the decision positively impact patients, families, employees, or the community? Does it consider their rights, needs, and perspectives?
- · Does the decision address or avoid enacting colonialism and discrimination?
- Does the decision enable trust in the organization or the health care system?

**About the Values Enacted** 

 Does the population needs justify the decision? (Greater need justifies allocating more resources).

- Does the clinical prognosis justify the decision? (Greater expected benefits justifies allocating more
- Is the decision costeffective? (Addressing a need should not spend more resources than necessary)

resources).

Is the decision sustainable? (Allocating a resource now should not compromise the ability to meet future needs).

About Resource Allocation

Were all stakeholders involved in the decision-making process?

- Did the decisionmaking process take place following a timeline commensurate with the urgency, gravity and complexity of the situation?
- Is there a plan in place to implement the decision?
- Is there a plan in place to communicate the decision and how it will be implemented to the stakeholders?
- What can be learned from the situation faced?

**About** Implementation

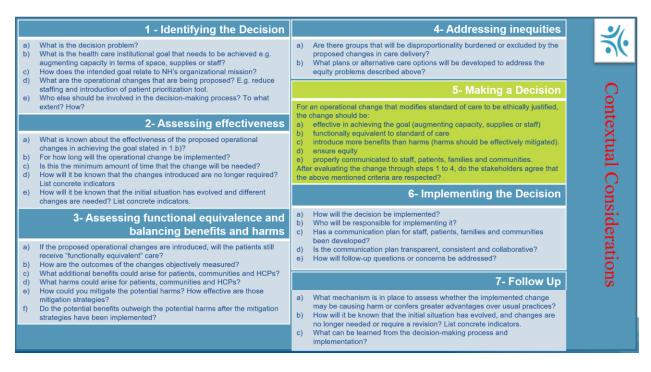
**questions:** The decision has not addressed relevant moral aspects. Consider to contact





## Appendix 8 - Surge Capacity Decision-Making Model

Demands for clinical care resources may exceed supply due to factors such as physical space limitations, shortages of trained personnel, or insufficient quantities of specialized equipment. Under those circumstances, healthcare institutions introduce adaptive strategies to continue providing care despite the constraints. Those strategies represent contingency standards of care, a stage intermediate between conventional and crisis standards of care. This decision-making model helps leaders to assess the ethical acceptability of the operational changes to be introduced.





## Appendix 9 - Surge Capacity Decision-Making Model - Abridged

This abridged version of the Surge Capacity Decision-Making Model has been created recognizing that the conditions to go through a detailed decision-making process are not always present. This version summarizes the key ethical aspects that should be considered when introducing changes to standard of care.

# **Surge Capacity Decision Making**

For an operational change that modifies standard of care to be ethically justified, the change should be:

- a) effective in achieving the goal (augmenting capacity, supplies or staff)
- b) functionally equivalent to standard of care
- c) introduce more benefits than harms (harms should be effectively mitigated)
- d)ensure equity
- e)properly communicated to staff, patients, families and communities.

Do the stakeholders agree that the operational changes to implement respect the above mentioned criteria?

If you answer "Yes":
The decision likely addressed most relevant moral aspects. If questions remain, consider to contact the Ethics Service.

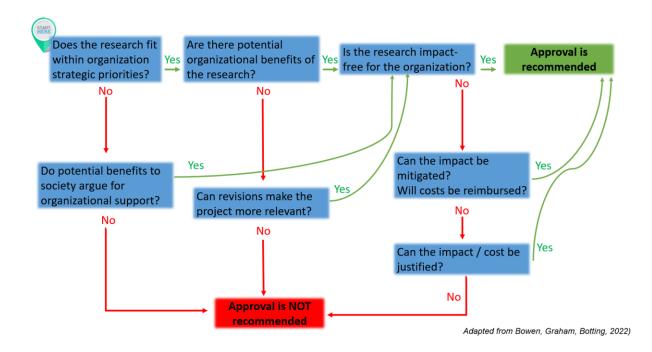


If you answer "No":

The decision has not addressed relevant moral aspects. Consider to contact the Ethics Service.



## Appendix 10 - Operational Approval Decision-Making Guideline





## Appendix 11 - Ethical Values which NH Upholds

<u>Autonomy:</u> Individuals have a right to self-determination, that is, to make decisions about their lives without interference from others.

<u>Beneficence</u>: Obligation to act for the benefit of the patient, protect and defend the right of others, prevent harm, and remove conditions that will cause harm.

Non-Maleficence: Obligation to not harm others.

<u>Justice:</u> Fair, equitable, and appropriate treatment of persons.

<u>Procedural Justice:</u> Accountability to fair and transparent processes in health care management.

- Openness and transparency: Any planning, any policy, and any actions deriving from such policies, must be transparent and open to stakeholder input as well as available to public inspection. All plans and all decisions must be made with an appeal to reasons that are mutually agreed upon and work toward collaboratively derived goals.
- *Inclusiveness:* This means that those making decisions should:
- involve people to the greatest extent possible in aspects of planning that affect them,
- take into account all relevant views expressed, and consider how all stakeholders have a fair opportunity to get their needs for treatment or care met,
- take into account any disproportionate impact of the decision on particular groups of people.
- Accountability: This means that those responsible for making decisions may have to justify the decisions that they do or do not make.
- Reasonableness: This means that decisions should be:
- Rational and not arbitrary or based on emotional reactivity
- Based on appropriate evidence, available at the time
- The result of an appropriate process, taking into account how quickly a decision has to be made and the circumstances in which a decision is made
- Practical have a reasonable chance of being feasible to implement and to achieve their stated goals

<u>Distributive justice:</u> It is concerned with the fair distribution of the burdens and benefits of social cooperation among diverse persons with competing needs and claims.

<u>Compassion:</u> Expression of care and concern for another person or group of people. It does not suggest any feeling of superiority towards others, but is instead a virtue that forms a bond between people.

<u>Equity:</u> It refers to social justice or fairness; and, as an ethical principle, it is grounded on distributive justice. Equity in health can be defined as the absence of socially unjust or unfair health disparities.



- Fairness: Everyone matters equally but not everyone may be treated the same. There are three competing forces in fair delivery of care and services that must be balanced.
- Persons ought to have equal access to health care resources (equality), however:
- Those who most need and can derive the greatest benefit from resources ought to be offered resources preferentially (*equity*), and
- Resources ought to be distributed such that the maximum benefits to the greatest number will be achieved (utility, and *efficiency*) and
- Resource allocation decisions must be made with *consistency* in application across populations and among individuals regardless of their human condition (e.g. race, age, disability, ethnicity, ability to pay, socioeconomic status, pre-existing health conditions, social worth, perceived obstacles to treatment, past use of resources).

<u>Stewardship:</u> Responsible use and management of resources in a way that takes full and balanced account of the interests of patients, communities and society at large, and accepts significant answerability to society. It encompasses the ethical responsibility to act on behalf of others and to honor the responsibilities of service, rather than to pursue one's own self-interest.

<u>Confidentiality:</u> Obligation to not to disclose confidential information given by a patient to another party without the patient's authorization.

<u>Truth-telling:</u> Responsibility to provide truthful information to patients as well as to respect their righto not to know such truth.

