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BCCDC Ethics Framework and Decision Making Guide

Effective: May, 2011

Reviewed: May, 2015

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BCCDC ETHICS FRAMEWORK AND DECISION MAKING GUIDE

The British Columbia Centre for Disease Control (BCCDC) is committed to fostering a culture of ethical awareness and responsibility; this document was developed with this in mind. Its purpose is to give consistency and clarity in guiding ethical action and in resolving ethical issues. The intended users are all staff and employees of the BCCDC. This document is in two parts.

- **I. BCCDC Code of Ethics.** The first part is a statement and description of that culture that we aspire to, it is the foundation for action, and it provides ethical input into decision making.
 - A) BCCDC Mandate
 - B) Terms of Reference, Key Concepts, and Definitions
 - C) Shared Ethical Values and Beliefs
 - D) Principles of the Ethical Practice of Public Health at the BCCDC
- **II. Decision Making Guide.** The second part of this document is a guide to aid in resolving ethical challenges and dilemmas when they arise in the practice of public health, and implementation of public health programs.

ACKNOWLEDGEMENTS

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Members of the BCCDC Executive Management Team

It is adapted from the content and format of the: *Principles of the Ethical Practice of Public Health*. [Public Health Leadership Society. 2002]

Thank you to the many hours of research, review, consultation and document compilation conducted by David. Without his work, interest and meticulous nature, this document would not have been possible.

A special appreciation to Bonnie Henry, MD MPH FRDP (C); Director, Public Health Emergency Services for her support, guidance and participation in document review.

Without the support and knowledge of the many BCCDC groups, the completion of this document would not be as meaningful and supportive to the public health work that BCCDC conducts across the province every day.

I. THE BCCDC CODE OF ETHICS

The point of embarkation is the BCCDC Mandate. A description of key concepts, terms of reference, and definitions provides context for the values and principles of the Code. The practice of public health at the BCCDC is guided by established and accepted ethical principles based on a core of shared values. This code is adapted from the *Principles of the Ethical Practice of Public Health*¹ with significant contributions from other works and scholars. The Code is intended to integrate with other relevant ethical codes; to that end, all employees and staff of the BCCDC shall adhere to the PHSA Code of Ethics² and shall also adhere to their own Professional Codes of Ethics.

BCCDC MANDATE

Our mandate is leadership in protecting and promoting health, preventing harm, and preparing for threats. We achieve this through collaboration, integrity, excellence and service.

TERMS OF REFERENCE, KEY CONCEPTS, AND DEFINITIONS

Public health ethics involves a set of terms and concepts that are unique, or used in unique ways. A more complete understanding of the principles of the Code will be enhanced by a familiarity with these terms.

- **Health:** BCCDC adopts a notion of health that is consistent with the WHO statement: Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.³ Nowhere is this broad definition more important than when trying to define public health.
- **Public Health:** “Public health is what we, as a society, do collectively to assure the conditions in which people can be healthy.”⁴ This is the core of the BCCDC mandate. Public health is concerned primarily with the health of the entire population. As a starting point for an understanding of public health ethics, public health systems consist of all the people and actions, including laws, policies, practices, and activities, that have the primary purpose of protecting and improving the health of the public.^{5,6}
- **Ethics:** There are many ways to define ethics. As an academic discipline it is concerned with the notions of right and wrong, good and bad, etc. For the purposes of this Code, ethics largely refers to “normative ethics” and in that sense this Code is concerned with questions of “What *ought* to be done?” and “How *should* we behave?”. Answers to these types of questions are aided by examining and contemplating the Values and Principles.
- **Public Health Ethics:** Is the moral foundation for the practice of public health. It is important to recognize that traditional bioethics and clinical ethics (whose focus is on individuals) does not map directly onto the terrain of public health ethics (whose focus is the population). Whereas clinical ethics is often concerned with individual decision making, public health ethics is concerned with procedures, programs and policies for community well-being. To what extent it is just and proper for public health to involve itself in the lives of individuals for the betterment of the population is the fundamental source of many of the challenges, dilemmas and tensions in public health ethics.
- **Respect for Autonomy:** Respecting a person’s capacity and right to make decisions for him or herself, based on his or her own values preferences and goals. It is, in essence, a respect for persons’ freedoms

and liberties. It is this respect for autonomy that is the source of tension with competing concepts of justified paternalism and justified harm prevention.

- **Paternalism:** Acting like a father or parent to another. It is the idea of restricting a person's freedom for his or her own benefit, or protecting that person from harming him or herself. It implies a judgment that the person may not fully understand what is in his or her own best interest, or the risks involved in his or her decisions.
- **Harm:** Harm and burden are often used interchangeably, and are often used in conjunction with the word risk (which is the probability of a harm multiplied by the magnitude of the harm). Broadly speaking, harms or burdens in the realm of public health ethics can be of three types:
 - Breaches of privacy or confidentiality.
 - Compromised autonomy or personal liberty.
 - Infringements on justice; the unequal distribution of harms (or goods) when public health interventions target specific populations.⁷
- **"Harm Principle":** This refers not to harm in the public health sense as noted above but to individual hurt and suffering. It is a fundamental concept in public health ethics and is attributed to John Stuart Mill: "That the only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others."⁸ This is essentially a justification for intervention by the state, and a warrant for infringements on personal autonomy in the name of harm prevention or reduction. In public health practice this is most commonly considered in the context of a duty to protect the public from harm.
- **"Precautionary Principle":** In the face of scientific uncertainty, it is this principle that warrants public health interventions when there is the theoretical risk of harm to the population even before all scientific data are obtained. Lack of full scientific certainty should not be a reason to postpone action in the name of the prudent concerns of the population or the environment.
- **Distributive Justice:** Fair allocation of resources for all community members based on legitimate criteria appropriate to that particular context. It is based on the idea that people are equals and should receive equal consideration in distribution of scarce resources. Furthermore it means that people should not be discriminated against based on morally irrelevant factors (e.g., ability to pay, social status), and that goods are distributed according to need (equitable distribution). Distributive justice entails the fair distribution of both benefits **and** harms and risks among a population.
- **Transparency:** In public health transparency is a core principle. It is desirable to cast a wide net in securing the input of as many stakeholders as possible in the development of a program. Transparency must also be maintained in the implementation of a program and in the practice of public health by sharing information derived from public health interventions.
- **Proportionality:** This is the notion that any public health intervention should be proportionate to the threat faced, and that measures taken should not exceed those necessary to address the actual risk.
- **Public Justification:** This is related to transparency. When a public health program threatens to infringe on the liberties of an individual or community, public justification is the notion that the agency has a responsibility to explain and justify this infringement.⁶
- **Reciprocity:** This is the notion that every means possible should be sought to aid the individual in complying with the requests and impositions. In addition, complying with the public health program may

impose sacrifices and burdens and in whatever way possible these should be compensated by the program or the agency.⁹

- **Privacy:** Privacy pertains to people; it is the right of individuals and groups of people to seclude themselves from others, and the notion that others are barred from prying in on them or their affairs. Privacy is fundamental to a respect for persons and respect for autonomy. People and groups have a right to personal privacy, and have a right to keep their information private. Balancing this right with the public health obligation to protect others can be a source of moral tension.
- **Confidentiality:** Confidentiality pertains to information; it is the concept that information should be kept safe and only be revealed to duly authorized persons. The scope of that authority is narrow, carefully defined, and scrupulously defended.

COMMON ETHICAL VALUES AND SHARED BELIEFS AT THE BCCDC

The following values and beliefs are key assumptions inherent to a public health perspective. They are values and beliefs relating to the nature of health, community, and knowledge as a basis for action. They underlie the Principles of the Ethical Practice of Public Health.

1. Health

- **All people have a right to the resources necessary for health.** The BCCDC affirms Article 25 of the Universal Declaration of Human Rights, which states in part "Everyone has the right to a standard of living adequate for the health and well-being of himself and his family...".¹⁰ The BCCDC concerns itself with the health of the entire population of BC.

2. Community and Environment

- **The duty of primacy of the BCCDC is to protect and to improve the health of the people of BC.** The BCCDC respects the value and dignity of every individual but it is an agency of public health and has a duty to protect the people of BC. The moral relationship between public health and its public is such that in order to achieve its goal of health promotion and protection from infectious and environmental disease (both new and emerging) it must on occasion invoke measures that are justifiably paternalistic and focused on harm reduction and prevention.
- **People are inherently social and interdependent.** They look to each other for companionship safety and survival. The rightful concern for individuality and the respect for autonomy of all people must be balanced against the fact that each person's actions affect other people.
- **Communities are more than the sum of individuals.** Communities are valuable. A community or population is an entity unto itself, and it is to this entity that the BCCDC directs its efforts, while upholding the value of individuals and respect for persons. In public health, the population is the patient.¹¹
- **The effectiveness of institutions depends heavily on the public's trust and this trust is earned through ethical interaction.** Factors that contribute to trust in an institution include the following actions on the part of the institution: truthful communication; transparency; accountability; reliability; and reciprocity.
- **Collaboration is a key element to public health.** Collaboration with the public is essential in carrying out the mandate of the BCCDC. Positive alliances between the people of BC and institutions such as the

BCCDC are a sign of a healthy community. In addition, interprofessional collaboration among the various divisions, programs, and professions at the BCCDC is essential.

- **Community engagement is important to the creation and implementation of sound public health policies and programs.** The BCCDC values direct contributions by community stakeholders to the development and implementation of policies and programs. The BCCDC obtains essential indirect and representative public input through its relationship with the Government of the Province of BC. It is this engagement that constitutes the “informed consent” of the people for the public health agenda.¹²
- **People and their physical environment are interdependent.** People depend upon the resources of their natural and constructed environments for life itself. A damaged, neglected, unbalanced or poorly constructed environment will have an adverse effect on the health of people.
- **Identifying and promoting the fundamental requirements for health in a community are a primary concern to public health.** While some programs at BCCDC are curative in nature, the BCCDC recognizes the value of addressing underlying causes and prevention. Because fundamental social structures and social determinants affect many aspects of health, addressing the fundamental causes rather than more proximal causes, more fully actualizes the duty of the BCCDC to prevent harm and to promote health.

3. Bases for Action

- **Knowledge is important and powerful.** The staff of the BCCDC seek to improve their understanding of health and the means of improving it through research and the accumulation of knowledge. The responsible accumulation of knowledge means then weighing the moral obligation of sharing information for the benefit of others, and the moral obligation to respect privacy and maintain confidentiality.
- **Science is the basis for much of our public health knowledge.** The scientific method provides a relatively objective means of identifying the factors necessary for health in a population, and for evaluating policies and programs to protect and promote health. The BCCDC recognizes the value of the full range of scientific tools, including both quantitative and qualitative methods, and also values collaboration among the sciences.
- **People are responsible to act on the basis of what they know.** Knowledge is not morally neutral and often demands action. Moreover, information is not to be gathered for idle interest. Public health should seek to translate available information into timely action. Often, the action required is research to fill in the gaps of what we don't know.
- **Action is not based on information alone.** First, in many instances, precautionary action is required in the absence of all the information one would like—in these instances it is values that drive action, not information alone. Second, policies are demanded by the fundamental value and dignity of each human being, even if implementing them is not calculated to be optimally efficient or maximally cost effective—in these instances too, it is values that take priority in informing action and in applying information to action.

PRINCIPLES OF THE ETHICAL PRACTICE OF PUBLIC HEALTH AT THE BCCDC

The following principles give expression to the concepts and values stated above. While not exhaustive, they are a clear statement of the normative behaviors and the virtues the BCCDC and its staff aspire to, and an enumeration of the ways the BCCDC is accountable to the people of BC. The BCCDC and its staff will follow these principles in the creation of policies and programs and in the practice of public health.

- 1. The BCCDC shall address, principally, the fundamental causes of disease and requirements for health, aiming to prevent adverse health outcomes.** This principle acknowledges that good health is derived at very fundamental levels. While some programs at the BCCDC are concerned with immediate causes and with curative interventions, it will not lose sight of the fact that health is derived from social determinants at more fundamental levels (such as clean food and water, and access to the means to prevent and treat infectious diseases) and it will include these in the scope of its activities.
- 2. The BCCDC aspires to achieve community health in a way that respects the rights of individuals in the community.** This principle acknowledges the common need in public health to weigh the concerns of both the individual and the community. There is no simple way to reconcile the perennial tension between respect for individual autonomy and paternalism; and between personal liberty and harm reduction. The BCCDC respects and acknowledges the inherent value and dignity of all persons, but the interest of the community is one of primacy and the point of embarkation for the programs of the BCCDC.
- 3. The BCCDC and its employees are committed to community engagement.** Wherever possible the BCCDC will provide and seek direct or representative input from community members in the development and implementation of programs. The BCCDC is committed to transparency in communicating with the public. The BCCDC is also committed to accountability to the public and must justify actions that threaten to infringe community or personal liberties.
- 4. The BCCDC will seek the information needed to implement effective policies and programs that protect and promote health.** This principle recognizes a mandate to seek information that informs actions and evaluate programs. Information will be gathered by the least coercive means possible and only out of necessity. Infringements on personal liberties (such as the collection of private information) must be justified.
- 5. The BCCDC will act in a timely manner on the information it has.** This Principle acknowledges that public health is active rather than passive, and information is not gathered for idle interest. The BCCDC will act in accordance with its resources and within the mandate given to it by the Government of BC, based on available information. This principle also acknowledges that acting in a timely manner may mean acting on incomplete information in order to confront threats or prevent harm.
- 6. The BCCDC will promote the empowerment of vulnerable and disenfranchised community members, aiming to ensure that the basic resources and conditions necessary for health are accessible to all.** The BCCDC is particularly concerned with the marginalized and disempowered of BC. It is concerned with communities and populations at risk of harm. As well it is concerned with the vulnerable members of society such as children. It will seek to ensure a decent minimum standard of resources as a means to better health. This means a commitment to equality of opportunity and equitable distribution of health care resources.
- 7. The programs and policies of the BCCDC should incorporate a variety of approaches that anticipate and respect diverse values, beliefs, and cultures in the community.** The people of BC are a rich mosaic of ethnicities, cultures, generations situated in a wide range of environments. The BCCDC must have the flexibility and cultural competency to adapt to the many needs of this diverse province.
- 8. The BCCDC will ensure proportionality in its programs and activities.** It will ensure that the benefits will outweigh the burdens and risks. It wishes to ensure that both the benefits, and the burdens and risks will be

fairly distributed.⁷ Ultimately, on balance BCCDC programs and policies will be implemented in a manner that most enhances the physical and social environment.

9. BCCDC will properly justify the creation and implementation of its programs. Fundamental justification derives from the “harm principle”: that interventions and the exercise of power over individuals by the province and the BCCDC, is only warranted to prevent harm to others.⁹ But programs and policies must also show effectiveness, proportionality, and be done out of clearly established necessity.⁶

10. Programs and Policies at the BCCDC will have clearly stated goals and be of proven effectiveness. Any program at the BCCDC must have clearly defined objectives; furthermore there should be evidence of programs’ and policies’ effectiveness in achieving these goals.

11. The BCCDC and its employees will use the least restrictive or coercive means possible to achieve its goals. Any interference with personal rights and liberties carries a significant moral cost.¹² A variety of means are available to achieve public health ends but the least restrictive or coercive means should be sought and the most coercive means or the full force of state authority should only be implemented when lesser means fail.⁹ Even these lesser means will be used only out of clear necessity.

12. Whenever possible, the BCCDC will adopt a principle of reciprocity. Once a public health program is deemed legitimate, every means possible should be sought to aid the individual in complying with the requests and impositions. In addition, complying with the public health program may impose sacrifices and burdens and in whatever way possible these should be compensated by the program, the agency or the province.⁹

13. The BCCDC will protect the confidentiality of information that can bring harm to an individual or community if made public. Exceptions (e.g., communicable disease contact tracing) must be justified on the basis of the high likelihood of harm to the individual or others. A perennial challenge within public health ethics is with the proper use and disposition of delicate private information. The BCCDC is informed by relevant privacy legislation. There is moral responsibility inherent in the “possession” of information about the people of BC.

14. The BCCDC will ensure the professional competence of its employees. This includes, but is not limited to, accreditation of the facility, and ensuring the proper licensure and credentials of all its professional employees.

15. The BCCDC and its employees should engage in collaborations and affiliations in ways that build the public's trust and the institution's effectiveness. This principle underscores the collaborative nature of the BCCDC. It and its employees must have positive relationships among the divisions but also healthy and ethical relationships with institutions outside the BCCDC. This includes healthy relationships with government, research institutions, private industry, etc. Any conflicts of interest generated by these relationships must be disclosed and avoided.

II. DILEMMAS IN THE PRACTICE OF PUBLIC HEALTH: A DECISION MAKING GUIDE

Inevitably the above principles and values may support two or more divergent goals; this is the essence of an ethical dilemma. In our personal, professional and organizational life, we often struggle with issues for which no single "right" answer seems evident. The interface of the BCCDC with the public and the individuals in its clinical programs can create ethical tensions and challenges. As well, decisions about prioritization and resource allocation are unavoidable and create ethical concerns about the distribution of burdens and benefits.

At the BCCDC, ethical problems and dilemmas should not be suffered alone. The first step is to reach out to colleagues and leaders for support and guidance. This should include supervisors, operations leaders, and the physician leads of the division. If such a discussion does not reveal a solution, or if a course of action is not apparent, the following process is suggested as a decision making guide.

In these situations, it is important to think through the many factors that are at stake. The purpose of this decision making framework is an attempt to reflect ethically on the apparent problem and its stakeholders, the facts of the issue, the relevant guidance from established policy and law, and an analysis in light of the relevant ethical and moral principles in order to begin decision making that optimizes satisfaction and addresses concerns of all stakeholders. This framework is intended to represent a fair process—fair processes build trust among stakeholders and lead to collaborative and consensual outcomes.

1. Identify the Ethical Question.

- What is the issue that needs to be addressed?
- Can this issue be simply stated with the use of some of the terms listed above?

2. Identify the Stakeholders.

- Who needs to be a part of this decision making process? Be as inclusive as possible while keeping the decision making process manageable. Sometimes a stakeholder (such as an entire community) cannot be physically present, but their interests must be acknowledged and accommodated.
- Key players are: the individual (patient, client etc) or community affected; the staff member(s) who are grappling with the issue; the physician lead and operations leader.
- Persons from other divisions should be brought in if their division is affected or if there are people from other departments with expertise in managing these types of problems. This may also include legal counsel or privacy advisors.

3. Clarify the facts, gather information.

- What are the relevant known facts?
- What facts need further exploration to inform a decision?
- What information is simply unknowable?
- Have all stakeholders been able to represent their views of the facts?

4. Analyze the problem in light of the values and principles in the Code. Try to identify the origins of the tensions from the conflicting values and principles.

- What principles or values are in conflict? What moral intuitions ("gut feelings") are in conflict?
- Can this problem be described by the terms of the Code and in relation to the values and principles of the Code? If possible try to identify which values and principles seem to have priority.

- Competing interests also generate and contribute to ethical issues: be wary of conflicts of interest, real or apparent, that bear on the issue at hand.
- What are the possible consequences in terms of benefits, and risks and harms?

5. Identify relevant legal and normative guidance:

- a. Legal and legislative considerations.** What is the relevant legislation bearing on this issue? Should legal counsel be sought?
- b. Local policy and procedure of the BCCDC and PHSA.** What policies and procedural tools have bearing on this issue?
- c. Professional codes of ethics.** Most staff of the BCCDC have a professional code of ethics for their given vocation and these codes can be helpful in informing decisions and actions.
- d. Research guidelines.** Research is a large part of the activities of the BCCDC and there are well established guidelines and procedures for addressing research ethics questions. If this issue involves research, research ethics guidelines such as the TCPS2¹³, and departments such as the UBC Office of Research Services should be consulted.
- e. Moral intuition and ethical considerations.** All people have a sense of right and wrong, these moral intuitions should not be ignored but rather explored and discussed as a legitimate source of guidance in decision making.

6. Identify possible courses of action.

- Are there principles that appear to have priority?
- Are there legislative or policy statements that have compelling force?
- What are some of the alternatives?
- Sometimes doing nothing or making no changes is a legitimate consideration.

7. Make a decision.

- Are all the stakeholders adequately represented? Has this decision been deliberative? It must be recognized that sometimes compromises have to be made.
- In decision making, the ideal is unanimity, if the stakeholders are not unanimous how is the decision to proceed? Can consensus be reached or will decisions be based merely on majority opinion?
- Why is this best decision?
- It must be acknowledged that sometimes there is more than one answer possible. It is important that the decision and the actions that flow from it are ethically defensible and made in accordance with the principles of the Code.

8. Implement a decision.

- What is the plan of action for communicating the decision?
- Develop a strategy for implementation: what actions need to be taken and by whom?

9. Evaluate the decision.

- How will the decision be evaluated? By what criteria will the outcomes be measured and validated?
- Was this the right decision?
- Should revisions to the decision be made? Should revisions to policies and programs be contemplated? Do new policies need to be created?
- Do new ethical issues arise?

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