University of Alberta

# Ethically Justified System-Level Decisions in Health Care: Toward a Decision Support Workbook for Healthcare Leaders

By

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# ABSTRACT

In Canada, health authorities are largely responsible for meeting the global health needs of regional populations. Leaders of these organizations have to make difficult system-level decisions, from program prioritization to system organization and management. This dissertation engages two research questions. First, what makes a system-level decision ethically justified? Second, how can leaders be assisted to make better decisions?

Normatively, I argue that dominant models of applied ethics that defend substantive ethical principles do not deliver compelling enough direction in the context of complex, pluralistic societies. Instead, I support a process-centred approach grounded in deliberative democratic theory. I find this approach conceptually superior and consistent with the values embedded within Canada's healthcare system. I defend five clusters of recommendations to leaders for making decisions consistent with deliberative norms: They should a) appreciate the evaluative nature of decision-making and commit to transparency and democratization within the system; b) attend to internal decision dynamics, directly consider substantive values immanent in Canadian health care, and make their decisions and justifications public; c) ensure decisions are appropriately supported with education, communication, sustainability, downstream support, and evaluation and review plans; d) develop and implement a comprehensive public engagement approach; and e) develop and implement a comprehensive staff engagement strategy.

For the practical question I consult literatures on decision-makers' perspectives and the content and design of training materials. In a sixth recommendation cluster I argue that a decision support instrument should include processes that are systematic and transparent, inclusive, sensitive to context, have a clear role for evidence evaluation, facilitate critical engagement of the user, provide practical direction about decision processes, and model what good engagement requires. I then recommend a values-based system-level decision workbook as a resource for leaders. I describe the key elements of such a resource and report on a pilot study conducted with leaders at the Fraser Health region in British Columbia to test the context and content validity of a workbook prototype. Finally, I offer suggestions for comprehensive qualitative testing of an instrument.

For Rafeeq, my *jaan-e-man*.

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I am indebted to a number of individuals, teams and organizations for their support of my research. Without this I would not have been able to undertake and complete this project.

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I have undertaken this research while working full time. The organizations I have worked with have supported my work in various ways. Accordingly, I am grateful to Fraser Health (FH), Providence Health Care, and the Provincial Health Ethics Network of Alberta (PHEN). At FH I thank Dr. Tony Taylor in particular for his ongoing support of my work and for ensuring that reflection on values is systematically brought to healthcare decision-making. At PHEN I thank my mentor and colleague Al-Noor Nenshi Nathoo for his friendship and commitment to goodness.

My research is practice oriented. I have gained invaluable insight into the bridge between theory and practice from the many clinicians and administrators that I

have had the good fortune to work with. Particular groups that I single out for their hospitality to my work include senior leadership at all of the above organizations, teams working on influenza pandemic planning in Alberta and at Fraser Health, and the clinical and administrative leaders at Fraser Health who participated in the qualitative research component of this project.

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# INTRODUCTION

*A region must decide how to allocate a one-time five million dollar supplement to its budget. The region's leaders must choose between:*

- *Putting the new funds towards improved emergency room equipment,*
- *Attracting more physicians,*
- *Reducing the waitlist for hip replacement and cataract surgeries,*
- *Creating a new harm reduction program including a safe injection site,*
- *Developing programs aimed at increasing access to services for minority groups,*
- *Creating a new child dental health program,*
- *Developing a suicide prevention program,*
- *Enhancing the community schizophrenia services, or*
- *Developing teen family planning services.*

*There are many ways this decision might be made. One option might be to conduct a needs assessment and then to allocate resources in relation to the proportional burden of disease. Other alternatives include funding those programs that meet the strategic direction of the region, funding those programs that meet the strategic goals of the government, and following the dictates of the most powerful or vocal lobby group in the region (including members of the organization's executive).*

*What advice would you give to the leaders charged with making this decision?*

## Statement of the Research Problem

The central question of this research project is two-fold. On one hand is a philosophical-normative inquiry: what determines the right or ethically justified answer to this type of question – decisions made at the system-level within Canada's regionalized public healthcare[1] system? On the other hand is a practical-operational question: how should

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[1] Note: "healthcare" will appear as one word when it is an adjective and as two words, "health care", when used as a noun.

leaders who are regularly engaged with this type of question be assisted to make decisions that are more ethically justified?

The normative dimension of the issue requires an account of what makes a decision ethically justified. Dominant approaches from moral and political philosophy evaluate good decisions by how well they live up to one or more substantive principles or values, such as respect for individual rights, maximizing overall utility, protecting community solidarity, or equality of outcome among human beings. In order to make a sound decision, one will need to take a compelling account of these competing approaches.

The quality of a strategy for assisting leaders with system-level decision-making will need to be evaluated by how well it leads to decisions that are consistent with the normative demands as identified in the first dimension of the research question, and by its practicality. Assessing practicality will require a description of the barriers that exist for decision-makers and what strategies would help overcome these. Recommendations of strategies will need to be made in view of competing approaches, with arguments for why the recommended approaches are superior – both for their practical merit and their coherence with normative demands.

There would be many benefits from a research project that advanced knowledge on these two questions, including policies that are better justified; more effective decisions; greater compliance with decisions by those affected; and decreased moral distress on the part of those working within the system. However, this project is driven by more than a desire to improve policy-making, and thereby planning, delivery, and evaluation of services within the health system. It is chiefly motivated by its immediate relevance and importance to my work as a bioethicist. Accordingly, the practical output delivered by the research project is a values-based, system-level decision-making workbook for leaders in health care, which individuals in decision-support roles can use to help leaders in the system with decision-making.

## The Context

In Canada's public healthcare system, responsibility for health care is largely within provincial jurisdiction. In most provinces, this authority has been devolved to regional health authorities, which are responsible for meeting the global health needs of the populations residing within their geographic boundaries. Leaders of these organizations must make difficult system-level decisions on a regular basis, such as what basket of programs and services to provide.

These organizations have hierarchical leadership structures, being governed by a board of directors and guided in planning and operations by senior executive teams. Several layers of leadership, with titles such as Executive Director, Medical Director, Chief, Director, and Manager, support these senior executives. Then, there are more local leaders who guide the work of *front-line* staff. Each year, budget decisions are usually made at various levels through some hidden process (Gibson, Martin, & Singer, 2005). Within programs, staff and middle management determine which programs should be supported and to what extent. At higher levels, as regional health budgets are augmented or trimmed, executives develop organizational priorities and determine what specific programs will receive special attention.

Clearly, many system-level decisions in health care as messy, including questions of resource allocation Specifically, questions are messy when:

- they involve the allocation of scarce resources to advance health and well-being within a health system that is large, complex, and increasingly specialized,
- acute care services receive disproportionate attention relative to their place within the broader determinants of health,
- the very notions of health and well-being are contested, and
- the evaluative nature of these decisions either remains implicit or goes altogether unrecognized by the decision-makers.

This messiness is exacerbated in the context of a liberal, pluralistic, democratic political system that is founded on ideals of active citizen involvement, but where norms of justification are contested, where citizens come from a wide diversity of cultural backgrounds, and where there are disparities of knowledge, money and power. Against this backdrop, decision-makers must balance responding to the needs of their communities, political pressure from the provincial level of government, political commitments to constituency interests, and the demands of special interest groups, often through the media.

Notwithstanding this messiness, these decisions must be (and are) made daily across the country – albeit in a less tidy manner than is suggested by the example with which this dissertation began. In any given month, health regions might be approached for funding requests for new housing for the mentally ill, more hospitalist[2] positions in hospitals, better information management infrastructure, remuneration for physician consultation on administrative matters, or more surgeries to decrease wait lists. As dreams and demands regarding what might meet the needs of a region's strategic priorities far outweigh the resource supply – including human, capital, financial, and other resources – difficult trade-offs must be made.

Emanuel (1991) suggests that there is wide agreement about the ethics of allocating resources at the micro- or individual- level, in that most people believe that anyone with health care needs ought to have equal access to the services that meet those needs. If an organ is available, everyone who needs it should have an equal chance of receiving it, regardless of how this process is to be worked out and understood. Although this may be true, there is significant controversy at the program or meso-level, where the allocation of particular services is determined. Here, ethical tensions must be worked out between the good of the many versus the good of the few, between doing everything to extend the lives of individuals living today and between saving life at all costs and facilitating a dignified death. A significant gap in attention to this level of decision-making has been identified (McDonald, 2001, Mitton & Donaldson, 2003a-c). In a pluralistic, democratic society, the question of what ethical principles should inform this process is extremely complicated, controversial, and unavoidable.

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[2] Hospitalists, a relatively new category of care provider, are family physicians working, mostly on an hourly wage basis, in hospitals following the care of those patients without a family doctor.

The difficulty lies in the fact that leaders at this level are charged with making decisions but lack sufficient direction and the moral mandate for making these decisions unilaterally. They lack direction because different moral principles lead to different answers, and leaders do not know how to prioritize and balance these. They lack the moral mandate because they are either appointed by elected officials or hired by those who have been appointed. In a context committed to rich democratic norms, this leaves them too far removed from the public whose values are meant to inform these decisions. In order to ensure that meso-level prioritizing of services appropriately reflects the values of the society, a principled process for ranking these services is required.

## Methods & Outline

This research project relies on three distinct but related methods. In Chapter One, I use the methods of ethics analysis to examine the question of ethical justification, and contrast principle-driven and process-driven approaches. Drawing on moral theory, conventional models of applied ethics typically focus on substantive ethical principles that are regarded as morally authoritative, principles such as distributive justice, equal opportunity, equal outcomes, social utility, and respect for autonomy. Principle-based approaches resolve ethical tensions by applying principles to cases.[3] Using a principle-driven approach, one might first explain how favoured principles apply in the context of the decision, and then analyze the various alternatives to determine which is most consistent with these favoured principles.

In this chapter, I offer a theoretical argument about the limits of moral theory for resolving matters of public policy. I argue that principle-based approaches are important because they provide valuable insight at the theoretical level about the content and application of different substantive principles. In the context of modern, pluralistic societies, however, moral theory does not provide enough direction for the process of policy-making, particularly in light of the challenges of diversity, inequality, and complexity. With any substantive approach, one might legitimately ask why this favoured

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[3] The most pervasive such approach in bioethics is set forth by Beauchamp and Childress (2001) wherein the principles of respect for autonomy, justice, non-maleficence and beneficence are defended.

principle should be preferred over others? In societies that are committed to the value of democracy, the authority for adjudication between values rests with those affected by the decisions in question. Where principle-driven approaches focus on questions of *what*, on the content of decisions, process-driven approaches focus on the *how*. How is the public to inform the decisions made? With a focus on decision-making processes, Chapter One argues for a turn to political theory explain how decision-makers should establish which values should guide public policy and decision-making at the system level. Turning to the deliberative democratic theory, I end Chapter One with an argument in favour of this theory over principle-driven approaches.

In Chapter Two, I articulate a process-centred political theory based on my interpretation of deliberative democracy. Theorists from this tradition argue that a rich deliberative public sphere must be cultivated, wherein the values of respect, equality and inclusiveness prevail, and where issues of public policy are vigorously raised and engaged. Formal decision-making should then be responsive to these broad and informal deliberations in the public sphere. These theorists seek to explore the parameters of meaningful public participation in public policymaking, with a focus on the public reason-giving process for identifying and justifying substantive values to inform public policy (Chambers, 2003). There is disagreement among deliberative democrats about the relationship between the two tracks of deliberative democracy. Some theorists argue that society is too complex for a direct linkage between broad public deliberation and the formal policy-making process (Habermas, 1996). Others argue for a close linkage between the two, in order to ensure popular sovereignty (Bohman, 1996). Theoretical reflection on such questions is crucial, because it bears directly on the practical question of how a region ought to engage citizens in policy-making such as for program-level (meso-level) resource allocation.

The normative claim that moral authority in a democracy rests with those affected by decisions and the descriptive claim that this norm is favoured in the Canadian context are central to the move from moral theory to political theory. This manoeuver draws on critical theory methods. In Chapter Three, I will use these methods to identify the values immanent in and intrinsic to health care in Canada, and reflect on the implications of these value commitments. The general idea behind critical theory is that, because society does not represent a blank state of value commitments, we should begin by understanding the values embedded in a society, and then critically reflect on these to evaluate their justifiability. Young (2000) describes this method, stating

> *A critical theory does not derive...principles and ideals from philosophical premises about morality, human nature, or the good life. Instead, the method of critical theory... reflects on existing social relations and processes to identify what we experience as valuable in them, but as present only intermittently, practically or potentially.* (p.10)

In Canada, if one examines the context of health care delivery – ranging from existing legislation such as the Canada Health Act to the various public inquiries about the values of Canadians as they inform the vision of the system – certain value commitments become apparent, embedded within the existing arrangements, social relations, and processes of Canada's regionalized healthcare system, and the broader social arrangements of this context. Furthermore, I suggest that process and content criteria derived from these values can be used to evaluate whether decisions made in the system are ethically justified.

Although some might characterize the search for the common or core values in a community of 30 million people from diverse cultural, linguistic, national, and religious backgrounds is a fool's errand, Canadians' values concerning their healthcare system do seem to cohere. Indeed, in many respects, these are said to form a Canadian national identity. As an illustration, in comparing the health systems in Canada and the United States, Canadian values suggest a strong lean toward a liberal egalitarian perspective, relative to the Americans' more libertarian approach. Of course, neither of these national systems are formally bound by these respective perspectives, as there are market examples in Canadian healthcare (such as for dental services and pharmaceuticals) as well as examples of publicly funded services in the U.S. (such as Medicare and Medicaid programs). Most observers would agree, however, that the identities of these two systems are distinct and clear.

In Chapter Three, I specifically illustrate five values that are of demonstrated importance to Canadians when it comes to health care:

- Participatory democracy and healthcare as a symbol of Canadian identity,
- Solidarity, compassion and equitable access to services based on need,
- Effectiveness, integrity of the system, and the provision of the highest quality services,
- Accountability, good governance and responsible stewardship of public resources, and
- Professional responsibility and integrity.

In Chapter Three, I provide descriptive evidence that these values are embedded in existing arrangements and our demonstrated commitment to them, and offer a fuller specification of what these values mean. Of course, the values I identify and specify are not uncontested. As the history of the Canadian health care experience continues to unfold, so does the balance between these and other competing values. This balance is always fluid, and remains in tension with every decision that is made. The purpose here is not to settle, once and for all, the question of Canadian values; rather, it is to help identify where we as Canadians have demonstrated a commitment.

As critical theory methods will be used to defend certain normative commitments, these will impact the practical-operational dimension of the research project – what decision-makers need to do to enhance the justification of their decisions, and the strategies that will assist decision-makers in making ethically justified decisions. In Chapter Four, I argue that the values derived from the work in previous three chapters lead to five clusters of operational recommendations leaders should follow for system-level decisions in health care to be ethically justified:

*A) Understanding And Key Commitments:* This cluster calls for leaders to appreciate the evaluative nature of decision-making and increase their ability to speak together about values and beliefs; to commit to a rich understanding of publicity and to the development of a public sphere around the healthcare system; and to understand the idea of democratic complexity and commit to democratizing the decision-making that happens at the system-level in the organization.

*B) Decision-Making:* This cluster calls for leaders to review and revise the internal decision dynamics at the region; directly consider substantive values immanent in the Canadian context in their decision analysis; make transparent the decisions made, the value-trade-offs these involve, and the justification for this balancing.

*C) Decision Follow-Up:* This cluster calls for leaders to anticipate and support decision follow-up with education plans to ensure that those who need training to implement decisions have this; communication plans to ensure that those that need to know about decisions are made aware of the relevant information; sustainability plans to ensure the long-term implementation of well-considered and justified decisions; downstream support plans to assist those who will be put in morally compromising situations as a result of the upstream decisions; and evaluation and review plans to ensure that the actual consequences of a decision taken match those anticipated, and to take advantage of any changes in facts or values that may arise.

*D) Public Engagement:* This cluster calls for leaders to develop a philosophy of public engagement, including identifying and refashioning existing forums to make them more deliberative; creating new deliberative processes within the public sphere, exploring areas where affected parties are not connected enough to have access to decision processes, and actively seeking to overcome this. It also calls for developing an interim public engagement approach for use until the broader public sphere is effective.

*E) Staff Engagement:* This cluster calls for leaders to develop a staff engagement philosophy strategy.

For decisions to honour the norms defended earlier, they need to follow these recommendations. Knowing what makes a decision ethically justified will not only show how to evaluate the quality of actual decisions, but will offer standards by which to assess tools that support decision-makers in meeting the normative standards. In Chapter Five, I explore literature on what decision-makers find useful, and on the content and design of training materials. This literature suggests that interactive resources are desired by leaders, and have the potential to offer meaningful support that provides clear, rational, and defensible direction, can bring communities of people together, and makes a central place for good evidence in decision-making. I capture this as a sixth recommendation cluster for the development of support resources for leaders:

*F) Utility Criteria:* This calls for processes that are systematic and transparent, inclusive, sensitive to the context; include a clear role for evidence evaluation; facilitate the critical engagement of the user about values (not just prescribe substantive answers); provide practical direction about decision processes and not be limited to theoretical reflection on these, and are interactive and model for users what good engagement requires.

In Chapter Five, I also consider two alternative approaches to providing support for leaders, particularly in the context of setting priorities. I evaluate each of these against the six clusters of operational recommendations. Furthermore, I show that "Accountability for Reasonableness," developed by Daniels and Sabin (2002) and enhanced by others such as Gibson, Martin, and Singer (2004 & 2005), and "Program Budgeting Marginal Analysis," adapted by Mitton and Donaldson (2003b) fail to meet the demands of deliberative democracy or provide enough practical direction to enable leaders to meet the standards of justification outlined in this dissertation.

Finally, in Chapter Six, I explore the practical development of a decision-making resource, such as a workbook, as recommended in the literature. Beginning with a brief review of the conceptual framework of the workbook, I proceed to describe the key elements of a values-based system-level decision support resource for use in the healthcare context. The contents of the workbook correspond to the operational recommendations in Chapters Four and Five, and are illustrated by reference to a sample workbook provided in Appendix B. I then describe and report on a pilot study, conducted with leaders at the Fraser Health region in British Columbia, to test the context and content validity of the sample workbook. Lastly, I suggest lessons learned from this study, both for the workbook itself and for broader qualitative testing of the tool, though the latter is beyond the scope of this dissertation.

It is my hope that this dissertation will contribute to continuing public deliberation. Ultimately, the warrant of my claims will be decided within such deliberation. My goal is to make a meaningful contribution to the ongoing debate among Canadians as to what values should guide decision-making in our healthcare system.

# CHAPTER ONE: ETHICAL JUSTIFICATION – PROCESS OVER PRINCIPLE

I begin this chapter by outlining some of the operating definitions and assumptions that guide my thinking about the normative and practical questions I consider in this dissertation. I then consider alternative approaches to justified system-level decision-making, and frame the debate between principle-based and process-based approaches to justification in health policy. After describing principle-driven models of moral theory, I set out several key challenges for an account of justification that relies on consistency with some substantive value or principle. I use examples from influenza pandemic planning which is occurring worldwide to illustrate the differences between these perspectives.[4] Finding principle-based alternatives unable to handle the challenge of reasonable social pluralism, I defend a turn to the procedural accounts offered by political theory for providing solutions to challenging health policy issues.[5]

## Health Care, Health Policy, and System-Level Decisions

### *Health care*

Callahan (2002) suggests that medicine is about caring for individual patients, in order to achieve goals in four broad areas:

- preventing injury and promoting health,
- relieving pain and suffering,
- curing those who can be cured and caring for those who cannot be cured, and
- avoiding premature death and pursuing a peaceful death.

Here, medicine is understood as the complex of activities involved in providing medical care, including the services of those in the fields of nursing and other allied health professions. Public health is not about curing or caring for individual patients.

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[4] For the last two centuries, the world has witnessed an influenza pandemic every 11 to 40 years. The next influenza pandemic is expected to strike at any time, and planning is currently underway across the world, from the international stage to the very local level. See Public Health Agency of Canada (2006).

[5] I anticipate that those interested in this research project may come from diverse backgrounds. If this is accurate, then different readers will likely find some material that is new and some that is familiar in the first part of this chapter.

Rather, its goals are to reduce and ameliorate overall trends in morbidity and mortality for populations, through means such as health surveillance, disease and injury prevention, and health promotion.

Decisions in health care are made at a number of levels. At the broadest (macro) level, decisions range from how the health system should be organized to how much money should be spent on health care versus education and other public goods. At the most particular (micro) level, questions range from which patient should receive the heart transplant to how to deal with the home care patient that refuses his medicine. Between these two levels is the organization or program (meso) level. Questions at this level include whether resources should be allocated to more hip replacement surgeries, more ICU beds, or additional illness prevention programs. An even higher level of decision-making takes place at the global level in health care, where international questions range from how to support the health needs of impoverished nations thousands of miles away to how to make sense of the wide disparities in health status in the lives of sister nations in an interdependent global community.

Influenza pandemic planning requires efforts in all areas of health care and at all levels of decision-making. For example, surveillance efforts will need to be coordinated at the global level, as the likelihood for most countries is that the first humans infected with influenza will be outside their national boundaries, and communication and coordination efforts will be required to localize this spread. Broad steps will be needed at the population (macro) level, in order to prevent or mitigate the spread of the virus. Plans will need to be developed for managing the supply of vaccines and anti-virals across the country and within provinces. At the meso level, will be needed to accommodate the high numbers of people that require some form of treatment. This will include those infected by the flu virus, and those the system usually treats. Teams of providers will need to determine what their practice will be when needs vastly outweigh resources, and where demands of family will be as compelling as professional duties. At the individual (micro) level, local leaders and teams will have to decide how to respond to individual care providers that are struggling to balance professional and personal responsibilities.

### Health policy and system-level decisions

Health policies are commonly understood as formalized decisions made about the health system. These are seen as the positions that organizations articulate as their official responses to key issues.[6] This understanding informs Pal's (2001) definition: "Public policy [is] a course of action or inaction chosen by public authorities to address a given problem or an interrelated set of problems" (p.2). Pal distinguishes between policy and both emergency responses to surprise problems and routinized administrative decisions. He argues that because these decisions are not part of the systematic response framework to specific problems, they are not properly to be considered policy. In my view this definition is too narrow. Emergency and administrative responses may not be an obvious part of a formal, systematized response to a problem. However, they do affect large numbers of people and do reflect the moral culture and climate of the organization within which they arise (Amy, 1987). Regardless of whether they are cohesive or muddled, these policies still represent a formal approach to system-level problems in health care. Callahan (2002) defines health policy as "the organization of those [methods of medicine and public health] into some overall financial and distributional structure designed to pursue the general goals of health care and, ultimately, of health." Consistent with this understanding, I suggest that discussions of health policy should include attention to all system-level decisions.

I am not overly concerned to win the contest of defining the term *policy*. Rather, I wish to indicate my interest in the justification of all decisions made by public authorities that affect groups of people – what I refer to as system-level decisions. These decisions include establishing rules of conduct (e.g. policies about when, where, and by whom smoking is permitted on institutional premises), determining what and how resources will be allocated (e.g. priority setting about programs and services), and protocols for how care should be delivered (e.g. attempted resuscitation guidelines). Beyond formal policies, system-level decisions include the responses of leadership, individuals, and teams to challenging situations that arise where no formal policy has yet been written or

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[6] These are recognizable as the ones that end up in big binders, consulted only when crises arise.

where existing written policy does not fit. An example of the former might be how to deal with physicians and staff who use external communication channels (such as the media) to voice dissatisfaction with internal grievances (such as conditions in emergency department waiting rooms). An example of the latter is whether or not to allow health care staff to accept personal gifts from patients experiencing mental illness, which goes against organizational policy, where denial of a gift might be a serious clinical setback.

To summarize, decision-making in health care can be divided into micro choices that concern particular patients (such as what the goals of care for a given patient are and what interventions might be appropriate for achieving these goals), and choices that are about the system (meso, macro, and global issues). Within the scope of health policy, the system-level view includes all decisions and guidelines that concern the structure and conduct within the health system. This includes the fields of public health and medicine.[7]

## Ethics, Politics, Moral Theory, and Political Theory

The standards used to evaluate system-level decisions in health care will be based on an understanding of what makes a decision justified or legitimate in the first place. A decision that is legitimate has moral authority: those who are affected by the decision have a moral obligation to follow it.

### *Ethics*

Ethics, as commonly understood, is roughly about right and wrong, good and bad. However, there is no common understanding when it comes to what makes something right or wrong, the appropriate subject matter of ethics, the appropriate sources of moral authority, or how decisions should be made. My approach to thinking about ethics begins with the fact-value distinction. All attitudes, decisions, and actions, made by individuals and collectives, in both personal and public arenas, are based on two important types of ideas: beliefs and values. Beliefs are what we take to be true about the world – our

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[7] Accordingly, I will use health policy and system-level decisions interchangeably in this text.

understanding of the facts. Values are what we think are important – things that we value.[8]

For example, as organizations plan for the eventuality of an influenza pandemic, they will have to decide the degree to which laboratory technicians and other care and service providers should be protected against contracting the influenza virus. Looking at the recent SARS experience, many decision-makers may choose to offer care providers with the n95 mask and anti-viral therapy as part of an appropriate protection scheme. It is believed that the n95 mask will prevent airborne viral particles from contacting the care provider. It is also believed that existing anti-viral drugs will help the body fend off the virus should it penetrate the body.

The first thing to notice is that all of these statements are assumptions about *the facts*, and are conditional statements about what consequences will result from various actions. We can usually tell when someone is describing their beliefs about the world because they use various formulations of the verb *to be*. "This *will* happen" is a statement of belief, and beliefs, of course, may or may not be true. A fact is a belief that is true.[9] The more evidence that we have for a belief, the more likely that it is a fact. So, the quality of a belief depends on the supporting evidence. The second thing to notice is that beliefs often rest on other beliefs. The belief that the n95 mask will prevent airborne particles from contacting the wearer rests on beliefs about how the virus is transmitted. The belief that existing anti-viral drugs will help the body fend off the virus rests on the belief that the existing anti-viral drugs will be effective against the influenza virus that will hit the world.

Another thing to notice is that beliefs or facts alone do not provide enough information to make the right decision in a situation. The facts must be evaluated from

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[8] The relationship between facts and values is complicated. For the purposes of this project, and particularly at this early stage of the discussion, I propose not to engage the philosophical debate about the distinction. I believe it will be possible and sufficient to recognize these types of ideas in health policy in effort to engage the questions of how such decisions ought to be made. For a closer look at the distinction see Brook and Stainton (2000).

[9] For a discussion of the beliefs/facts distinction and an introduction to epistemology see Brook and Stainton (2000).

the perspective of what is important in the situation. This in turn relates to broader notions of what is important in life. Believing the above about masks and anti-virals is not enough to justify the decision to provide them to all care providers. Decision-makers who choose to provide these protective resources to care providers might do so in order to protect worker health, build worker trust, minimize overall cost to the system, provide the largest volume of care possible to society, provide the best quality of care possible, minimize the spread of disease, and minimize the risk of death. They likely find one or more of these considerations crucially important. It is our values – the considerations we think are important and should guide conduct – interpreted against the backdrop of the world as we believe it to be, that lead us to judgments about appropriate decisions, actions, and attitudes.

In the above example, we have merely described a perspective, and speculated on the possible beliefs and values of the decision-makers who choose to provide n95 masks and anti-viral drugs to care providers. We have not critically engaged the question whether decision-makers *should* provide these resources to their physicians, staff and volunteers. Based on the approach recommended here, ethics is about critically examining the values and beliefs that guide our decisions, actions and attitudes. In other words, ethics is about evaluating whether our decisions, actions and attitudes are based on relevant beliefs that we have good reason to think are true, and values that we have good reason to cherish. An ethically justified decision, action, or attitude is one that is based on beliefs we have good reason for deeming to be true, and considerations we have good reason to hold as the most important in the situation.

The work of ethics can be broken down into three different activities (Jiwani, 2001). The first activity involves reflecting on behaviour and asking what a decision says about what the actor believes and what is important to her. This is called descriptive ethics, because it is an effort to describe (without judging) the values underpinning behaviour. The second type of ethics work requires that we ask what values others and we should live by. This type of ethics work is called prescriptive or normative ethics because it offers direction on how the world should be. The third activity of ethics involves bringing our attitudes and actions into line, as much as possible, with our cherished values. When one is interacting in the world and must decide what to do or how to act, this activity involves thinking about how to practically base a decision, action or response on the values according to which we should be living. This is known as practical or applied ethics, because it concerns the operationalization of our values into daily life. To evaluate *upcoming* decisions we, as individuals, teams, and organizations, want to explore what beliefs and values should inform these. To evaluate *past* decisions we want to understand the beliefs and values these are based on, what beliefs and values they should have been based on, and how these two match up.

In our example, the work of ethics is to determine if the decision to provide n95 masks and anti-viral drugs to care providers, as part of a protection scheme, is justified. To answer this we would need to know:

- Whether we have good reasons for our beliefs about the situation. Will the n95 mask actually prevent the influenza virus from coming into contact with wearers? Will it do so more effectively than an ordinary mask? Will anti-viral therapy actually be effective on the anticipated strain of influenza virus? How will the virus be transmitted? Will trust actually be built by providing these resources to workers? What is the perception of workers about the effectiveness of these resources? What is the expectation of workers about receiving these resources?
- What values should decision-makers hold as most important when it comes to the scheme of protection that should be offered to workers? Should concerns about the health of workers be most important? Or should concerns about trust between workers and the organization be most important? Or should minimizing financial costs be most important?

How adequately these questions are answered will determine the justifiability of the decisions made. If the decision about what to provide is based on sound evidence – beliefs that we have very good reason to think are true – and on a very well considered and defensible set of values, it will be more ethically justified. Decisions made with a poor understanding of the facts and/or based on values that have not been carefully considered and exposed to critical scrutiny will be on the ethically unjustified side of the spectrum.

One way to understand how basic values that guide our everyday decisions connect with broader values is to think about the distinction between instrumental values and intrinsic values (Frankena, 1972).[10] Instrumental (strategic) values are important to us because they give us something more important. For example, we may decide that providing workers with whatever resources they ask for is important to us when determining a worker protection scheme in pandemic planning. Here, meeting worker demands is important to us, but this is not likely important for its own sake. Rather, decision-makers probably believe that meeting worker demands will build trust between the workers and the system. This, in turn, will increase the likelihood of their reporting to work during times of worker shortages, which will allow the health care needs of more people in society to be met. Therefore, meeting worker demands is instrumentally important for meeting the health care needs of as many people in society as possible. This, in turn, is instrumentally important for saving as many lives as possible and increasing the overall health of the community. On the other hand, an intrinsic (inherent) value is something important for its own sake.

Another way to look at this is to reverse the links. That is, if peace, security and well-being for all of humanity are one's deepest values, then considerations such as tolerance, kindness, and the sharing of resources would likely be instrumental in advancing these causes. Furthermore, if we want to increase tolerance, kindness and the sharing of resources among a pluralistic humanity, then learning about and coming to a genuine understanding about the diversity of the world, and developing the knowledge and skills required to overcome barriers to meeting basic needs, are two values that would appear to be instrumental. Going deeper yet, in order to build the requisite understanding, knowledge and skills, having the youth in community stay away from lifestyle choices that impair their health, and their ability to think, learn and work, is probably essential, as is ensuring that educational opportunities are properly pursued.

There are several important implications to thinking about ethics in this way. First, on this approach, all decisions, questions, and issues have an important ethical

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[10] For a more in-depth discussion of values see Harman (2000).

dimension. This goes against the thinking of some who speak as if ethics was a distinct category alongside others types of questions of a clinical, financial, legal, or marketing nature. With this approach, such distinctions are mistaken – they implicitly privilege certain values and beliefs without first justifying them. For example, in the health care setting (both clinical and administrative), it is not uncommon to encounter individuals who focus on the issue of legal responsibility when they are struggling with the right way to handle a challenging case.[11] To limit the scope of how a problem should be resolved to the legal responsibilities of the parties involved is to say that the most important, if not exclusively important, consideration in solving the problem is obeying the law. There are at least two problems with this approach. On one hand, there are likely many other considerations that our decisions should take into account that are just as important as the law.[12] On the other hand, the law may fail to provide a convincing, complete, consistent, or comprehensive response to the situation.

A second implication of this approach to thinking about ethics is that there is no binary answer as to whether a given decision is justified. The answer will not simply be yes or no. Rather, there is a gradient along which the justifiability of a given decision, action, or attitude will fall. The extent to which a decision is based on well-considered values and beliefs determines how close it is to the justified end of the spectrum. Conversely, a decision will fall closer to the unjustified pole if it is not based on well-considered values and beliefs. The purpose of taking ethics seriously is to move decisions towards the ethically justified end of this spectrum.

When it comes to health care, then, any decision, whether clinical or administrative, is always made because the chosen direction responds to or achieves something that is seen as important. On one hand, ethics is about examining the values that underpin the means that health care uses to achieve its ends. For example, ethics involves asking what values should guide the patient-provider interaction in the clinical

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[11] This is particularly true of my physician colleagues.

[12] These might include serving the needs of those in our care to the best of our ability, understanding what a meaningful life looks like for those in our care and making decisions that are consistent with their values and beliefs, and understanding our own values and beliefs and making decisions that allow us to live with integrity.

encounter, considering values such as respect for autonomy, patient benefit, and provider integrity. On the other hand, ethics is about examining what the broader goals of the health system ought to be. For example, should the focus of the system, with its limited resources, be on health promotion, disease prevention, providing for acute needs, or facilitating meaningful dying experiences for those at the end of life? Ethics is relevant to health policy in that it prods us to ask what values should guide our society in determining the goals of our health system.

### *Politics*

What is the relationship between ethics and politics? In some views, ethics concerns the duties that situated individuals have to the particular individuals in their lives with whom they have personal relationships (Dworkin, 2000, Appiah, 2005). These duties are distinct from, and sometimes in conflict with, the self-interest of individuals and the general duties that individuals have to other human beings. Some also understand politics to be distinct from ethics in that politics is the realm of public affairs where decisions are made about the terms of association of individuals living together in a polity.

I am skeptical of these distinctions. In my view, all decisions, whether personal or public, have an important ethical dimension in that they are based on beliefs and values. These values include commitments to specific individuals and to generalized others. This includes all questions that are usually considered to be political, as politics is that domain of questions about decisions that are to govern groups of people living together in community. In terms of health policy, the questions about how society organizes itself and the guidelines that direct this organization are political issues, in that they are about the decisions that will govern people living in the same political community.

On this view then, like any decision, for political decisions, such as system-level decisions in the Canadian healthcare context, to be justified, they will need to be ethically justified, which means they will have to be based on well-justified beliefs and values. The challenge is determining what are the right values and beliefs.

## *Moral theory*

In this section, I sketch out the contribution of moral theory to this question. Much of moral philosophy concerns the development and critique of moral theories in effort to unveil the truth about the nature of the world, what a meaningful life involves, and what is important in human conduct. A moral theory is a conceptual structure, which aims to categorize and offers standards for judging various aspects of human behaviour, based on a set of assumptions about the world (Jamieson, 2003).

Different moral theories have different approaches to justification. Foundational approaches begin with basic beliefs and then construct consistent and defensible theories that logically flow from these basic premises. These basic beliefs are understood as either self-evident or directly justified by experience (Harman, 2000). Coherentist approaches suggest that basic beliefs about good decisions need to be justified by their relationship to other beliefs, but also grounded in everyday moral experience. I will sketch each of these approaches, applying each to a particular question in pandemic planning. This section is not meant to advance moral theory, but simply to provide an illustration for those readers unfamiliar with principle-driven approaches. This review of approaches from moral theory leads into a more global critique of principle-driven approaches; I argue that we need to turn to political theory if we are to make headway in resolving system-level issues in modern, complex, pluralist society.

Imagine that you have to allocate vaccines for an influenza pandemic. The vaccines are in very short supply. You could give the vaccine to the frail elderly, to young children, to the average middle class adult, to healthcare providers working in hospitals, or to emergency response workers. Who should receive the vaccine?

### ***Foundationalist Perspectives***

There is a wide range of foundationalist moral theories; in their overview, Beauchamp and Childress (2001) include:

- consequence-based theory, such as Utilitarianism, which emphasizes outcomes;

- obligation-based theory, such as Kantianism, which emphasizes the rightness of actions themselves;
- virtue-based theory, such as character ethics, which focuses on the moral agent;
- rights-based theory, such as liberal individualism, which emphasizes formal relationships between separate moral agents;
- community-based theory or communitarianism, which emphasizes the importance of shared meanings; and
- relationship-based theory, such as the ethics of care, which highlights the interdependencies of human beings and the connections between people.

So when it comes to questions of policy, such as various issues in influenza pandemic planning, each foundationalist theory favours particular principles. To illustrate how these perspectives in moral theory work, I consider several significant principle-driven approaches. For each, I provide a quick sketch of the perspective, suggest how it might apply in the context of allocating influenza vaccines, and flag major objections.[13]

### *The Libertarian Perspective*

The basic premise of this view is that, as individuals, our bodies are our possessions, and we ought to have the exclusive right to do with them as we please. The only limitation of this right is that we must not violate anyone else's ownership rights, including to their bodies. This premise is then extended to those things we justly come to claim as our property or that we have a hand in making. Thus, if I lay claim to some land – say by trading for it or by discovering it in its previously unowned state – and build a house, these possessions that I have acquired are extensions of myself. I have exclusive ownership, and no one should be able to infringe upon my property rights. Similarly, I have no justification to interfere with anyone else's property rights.

Narveson (1988) points out that any fundamental right can thus be understood as a property right. For example, the right to free speech is not a right to go around saying whatever one wants wherever one wants without constraint. Rather, it is to be understood

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[13] I am by no means seeking to refute these theories. My goal is simply to make readers aware of some common objections, preliminary to considering an objection that applies to the ensemble of foundationalist perspectives.

as the right to determine one's disposition in terms of what one says – anywhere that one justly has property rights. Based on this premise, no one, whether individual or state, has the moral right to force another to act in a way that he or she does not directly desire. One is justified in infringing on another's liberty only if it is to prevent or punish acts of physical assault, theft, or fraud.

Nozick (1974) offers a strong version of this claim, suggesting that while it may be true that a free market system is to the mutual advantage of members of society, this is irrelevant. The fundamentally important requirement of any system is to respect our basic rights to freedom and ownership of private property. These are the only relevant concerns for an acceptable theory of social organization. Goods, including health care, are distributed fairly only if they are traded on the free market. That is, it is important that there be no room for society to interfere with private interests who wish to develop, sell, or purchase the vaccine, regardless of equality or social consequences. If you can afford it, you should be free to trade for it in the market place; if not, you may be able to count on the charity of others. No one has any obligation to provide you with something that you need.

Two serious deficiencies with the libertarian position concern the voluntariness of contracts and unfair starting points. Imagine that a family is desperately in need of a good or service for the sustaining of life. This situation allows the person with the good to be traded for to have what might appear an unfair advantage in the trade relationship providing them with the ability to ask for much more than the good might be worth. If the person in need is desperate enough, he or she might be forced to agree with whatever conditions the person that has the good sets out. But to what extent is this trade relationship voluntary? The most important objection to the libertarian program is that it does not account for the fact that individual transactions of trade have a much wider impact that is not limited to the trade partners. For example, transactions entered into will result in a change in the socioeconomic situation of both partners. However, these transactions will also determine the socioeconomic starting points of future generations of the trading partners. But in no way can it be said that those future generations actually *deserve* the socioeconomic starting points, whether it be one of wealth and high status or poverty and social stigma, they will be given. As a result, some argue, measures to ensure some sort of equalization of socioeconomic status for these future generations are *required*, not only justified.

### *The Social Utility Perspective*

Utilitarianism is a theory of justice that does not rely upon a moral right to liberty – or any other moral rights. The theory focuses on the consequences of an action, and is concerned with maximizing the overall good in society, measured as *utility*. Whatever decision will result in the greatest overall utility is ethically justified.

Goodin (1995) points to three dimensions of utilitarian theory. The first of these is content – what is meant by the good or utility that is to be maximized. Hedonic utilitarianism is concerned with maximizing pleasure and minimizing pain. Preference utilitarianism is concerned about the satisfaction of individual preferences. Welfare utilitarianism takes the broader view that whatever is in the interests of an individual, including what they may not yet understand to be in their interest, is what should be maximized. The second dimension is who counts in the utility calculation. Some versions are concerned only with actual people and the actual preferences they have. Other versions are concerned about the utility consequences for all possible people, including future generations that will be impacted by decisions. The third dimension has to do with the object of the utility calculation. Act utilitarianism holds that individual acts should be measured for their consequences, decision-by-decision. Rule utilitarians, on the other hand, believe that it makes more sense to focus on general rules and adhere to those rules that will maximize utility.

In determining fair distribution strategies, utilitarians look for the allocation pattern that results in the best overall outcome. In the example above, we would look at all of the distribution patterns available to us, add up the good that results in each, subtract the harm that results from each, and then select the option that results in the most net good. The goal is to identify the distribution that secures the greatest overall good for the greatest number. By most utilitarian calculations, between the frail elderly, young children, average middle class adults, healthcare providers working in hospitals, and emergency response workers, the latter two groups should receive the vaccine because of the strategic roles they will likely play in improving the well-being of many others in society.

One interesting note here is that it is the enabling effect of giving vaccines to these groups that leads to the privileging of their needs. So, whatever allows these groups to function when their services are required would be ethically justified. Even if vaccines are believed to be ineffective by the scientific community (and there is uncertainty about this), if giving these to care providers will mean they are better able to carry out their work, then doing so is justified. Another interesting note that follows is that a special sub-group should receive priority: individuals to whom care providers have personal (as opposed to professional) commitments. That is, many care providers may not be able to serve the community if they are forced to stay at home caring for loved ones who are sick. Thus, utilitarian calculations may lead to the conclusion that we should offer vaccines to the close relations of care providers, in an effort to maximize the overall well-being of the community.[14]

Many worries are raised about the social utility approach. For example, in most cases it is difficult to know in advance what the consequences of a given pattern of distribution will be. Therefore, any utility calculation can only be a speculation, and may not actually maximize overall utility. Another concern is that it is difficult to weigh the relative good and relative harm that results from saving the life of one person while allowing another to die. Because these evaluations are subjective and controversial, how is one to know how the evaluations should be made? Similarly, good and harm in themselves are value-laden notions. As such, it is difficult to make the objective calculations that this approach requires. This approach is also counter-intuitive in some respects. For example, if two patterns of distribution result in equal outcomes, then there is no moral difference between the two on this approach, even if the most vulnerable in one arrangement are treated poorly, while in another their lot is significantly improved.

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[14] This specific question deserves much more careful analysis than is permitted in this space. The purpose here is to illustrate how this principle-based approach might work in this example.

The approach also raises concerns about treating people as legitimate means to collective ends. That is, on utilitarian grounds, it may be justified to place heavy burdens on small groups of a population if it results in increased aggregate well-being. But such distributions are in tension with commonly accepted intuitions that such arrangements are unfair.

### *The Egalitarian Perspective*

On this family of views, all human beings are morally equal and equally deserving of the opportunity to flourish. It assumes that human beings cannot be said to deserve the starting points we are born into, including the health, economic, social, or political status with which we are born. Accordingly, society must redistribute goods to overcome any arbitrary discrepancies in allocation of goods that occur in the natural lottery. This duty-based approach argues that society should to ensure, as much as possible, that the differences that result in society are deserved, not conferred.

Radical egalitarianism favours allocation strategies that aim at equalizing *outcomes* (Veatch,1986). The goal of redistribution is to make sure everyone ends up on the same level, even if this means that those who are worst off would be less well off in the more equal state than they would have been given an unequal distribution pattern. So how do we distribute the vaccine using this view? We distribute it to those whose health status is most compromised and who need the vaccine the most, in order to elevate them as closely as possible to the health status of the rest of the members of society.

One dissonance of this approach with the moral intuition of many is that it seems odd to favour distribution patterns where everyone is worse off, but with less disparity between status levels, to patterns of distribution where everyone in society is better off, though the gap between the worst and the best off is greater.

Moderate egalitarianism on the other hand is concerned that individuals in society should have equal *access to the opportunities* that are needed and allow them to flourish. For example, the principle recommended in Rawls' (1971) approach is that goods in society ought to be distributed equally, unless an unequal distribution would result in making the worst off better off than they would have been under more strictly equal distributions. This is referred to as the maximin principle, because it seeks to maximize the minimum standards for those in society. The pattern of allocation that best improves the situation of the worst off is preferred.

How should health resources be allocated using this approach? Rawls is concerned with basic political liberties. Daniels (1985) extends Rawls' theory, arguing that health is strategically important to our abilities to develop and achieve our life goals and plans, regardless of what these plans are. Thus, health care should be distributed according to the degree of limitation that illness or disease places on the individual's ability to live a good and meaningful life. Everyone should enjoy an equitable share of health care services based on need, unless those in the worst off positions are made better off by an unequal distribution. In the vaccine example, while giving the vaccine to those whose health needs are most compromised would serve the least well off, giving the vaccine to healthcare providers working in hospitals and to emergency care workers might serve the least well off even better. If so, then it would be justified to give the already better off (healthier) group the resources, because even though it would result in greater inequality, it would leave those in the worst off health situations even better off than if they were to receive an equitable portion based on need.

Both radical egalitarians and libertarians have concerns with this approach. Radical egalitarians find the inequality that is tolerated by this approach unacceptable. Libertarians, on the other hand, find the approach coercive, although less so than the radical egalitarian approach. Another worry with this approach is that it requires us to define what basic health care coverage means – and it is not clear how to do this. Daniels argues that this view will actually lead us to focus more on process values, and we will return to this issue below.

## ***Coherentist approaches: Casuistry and Principlism***

Rawls' (1971) method of reflective equilibrium exemplifies coherentist moral reasoning. He suggests that in trying to determine what is ethically justified we start by identifying our well-considered beliefs based on our experience. From these, we articulate broader principles that account for these beliefs, and then continue to check these principles against our considered judgments. As we continue this process of checking up and down, we achieve reflective equilibrium.

In bioethics two prominent coherentist approaches to theory development are casuistry and principlism. Casuistry focuses on paradigm cases, and uses analogical reasoning and practical judgment to learn from these cases in order to respond to new ones, thus building moral knowledge. This knowledge begins with basic maxims (which are not as concrete as rules or principles), and then emerges as principles over time as an increasing number of cases are considered. Principlism seeks to capture the key elements of persuasive moral theories in mid-level principles. These principles are prima facie action guides that are specified, weighed, and balanced in application to specific cases. Coherentist approaches also supplement foundational beliefs about right action and consequences with some appeal to both virtue and relational ethics. Kuczewski (1998) argues that despite protestations of their proponents to the contrary, the methods of casuistry and principlism are largely the same. Both rely on clear intuitions about paradigm cases to resolve challenging issues. Because of its influence on contemporary bioethics, I will consider the principlist approach more closely.

### *Principlism*

An early articulation of this approach comes from philosopher W.D. Ross (1930), who identified a number of conditional duties that individuals have, including fidelity (the duty to keep our promises), reparation (the duty to make amends for harms we have caused), gratitude (the duty to reciprocate good deeds done to us), justice (the duty to prevent or correct disparities between what people need or deserve and what they receive), beneficence (the duty to advance the interests of others), non-maleficence (the duty not to harm others), and self-improvement (the duty to improve one's own condition). These duties are conditional in that for any given circumstance the individual is to carefully assess the situation, critically reflect on which of these duties are most pressing, and then act in accordance with the requisite duty.

This approach has also been favoured by early Western bioethics, first in the principles for research ethics articulated by Beecher (1966) in his criticism of research practices in the health sciences, and then in *Principles of Biomedical Ethics* by Tom Beauchamp and James Childress (2001), which quickly became the eminent bioethics textbook. In their model, Beauchamp and Childress advocate that in working through difficult questions, four main principles must be considered: respect for autonomy, justice, beneficence, and non-maleficence. The solution to the problem that best meets these principles is the one that is most justified.

In the principle-based approach to pandemic planning, the process would involve identifying principles, learning from past experiences (such as the SARS epidemic), considering the expectations of the pandemic situation, and then using practical wisdom to apply lessons learned to the new context (Kotalik, 2003).[15]

Limitations of this approach become evident in some Canadian responses to the ethical difficulties raised in pandemic planning. For example, Kotalik (Ibid.) identifies two key principles in tension in flu pandemic planning: respect for autonomy and concern for the aggregate health of the population. He then goes on to offer following algorithm for resolving the types of questions that will be raised by an influenza pandemic:

> *For pandemic influenza planning, a moderate "communitarian" approach seems to be appropriate. Such an approach could be made operational by applying to each situation the following two rules:*
>
> *The degree to which restrictions of personal liberty are ethically permissible depends on the balance among three issues: 1) importance of public benefits; 2) the degree to which the rights and liberty of individuals are to be restricted in order to provide that benefit; 3) the distribution of both restrictions and benefits among the population.*
>
> *The restriction should always be minimally necessary to achieve the targeted common good.* (p.7)

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[15] Soskolne (2003) offers another public health example in the context of public health policy concerning indoor air quality.

One difficulty with this approach is that it inappropriately privileges the perspectives and the knowledge of some groups over others. It is an elite group that gets to interpret the values: what is in the public's interests and what counts as the common good. Another worry is that the approach uses and is based on language that assumes a positivist ideology. As the algorithm suggests, decision-makers are to calculate:

- the public benefit from the coercive action,
- the cost to the liberty of the individual, and
- the distribution of the costs across the population.

They should then devise a solution that maximizes the benefit and minimizes individual cost and unjust patterns of distribution (though not much is said about what patterns of distribution would be just). Aside from the fact that this utilitarian approach is misidentified as moderately communitarian, the approach assumes the primacy of the value of individual liberty and pits it against the value of justice. It also leaves it up to the decision-making body to define the public good.

The problem with posing the dilemma as between the interests of the individual and the interests of justice is that it becomes difficult to account for the complexity of the relationship between the two. In ordinary times, the relationship between healthcare providers and the community is complex. Healthcare providers rely on the community to support their training. The community confers special status on associations of providers, for example, in terms of self-regulation. Collectively, the community trusts the wisdom of the health system to help it understand the complicated relationship between the causes of illness and disease, disease processes, and the means for ameliorating health deficits.[16] At the same time, healthcare providers perform some of the most important work in society, such as providing care for the growing elderly population. They often work very long hours in difficult conditions, without appropriate recognition or compensation. As professional caregivers, they carry a double emotional load of supporting those who need help in healthcare institutions and fulfilling their own personal relational commitments.

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[16] We will see this addressed more in Chapter Three in the discussion of respect for professional integrity and accountability as a value immanent in Canadian health care.

In extraordinary times, the complexity of these relationships is exacerbated. To dichotomize the ethical dimension of the relationship between healthcare providers and the community fails to take into account the many ways in which healthcare providers and the community are interrelated (Lambert, Soskolne, Bergum, Howell, & Dossetor, 2003). It also fails to take into account the actual experience of most healthcare providers, especially those to whom much of the actual care-giving responsibilities fall, in both public and the private settings.

The problem with having decision-making bodies define the public good is that there is no direct way for the members of the community, healthcare providers, and others, to inform the discussion of how to handle the shortage of healthcare providers in the context of the complex web of interrelationships in society. All members of the community have an important role in helping define the public good. In times of crisis, however, these groups will have especially important and relevant understandings of what individual and community well-being requires. Not only that, but they will likely have the best information about strategies for balancing the many competing demands they will face.

One reply to the concerns raised in both cases is that it would be inappropriate (and politically inexpedient) to predetermine what the good looks like at the individual or the community level. This response makes the traditional liberal claim that, in light of the pluralism in society, it is important for public institutions to remain neutral. To specify the meaning of good would be to privilege some notions over others, rather than being sensitive to different conceptions of good.

This liberal argument shunts the question of the appropriate ends of medicine, an important complex of social institutions, away from the political arena to the professional and the personal, leaving particular individuals – physicians and loved ones who are to act as surrogate decision-makers – to make these crucial political decisions on a case-by-case basis. Yet, these individuals do not have the moral authority to make such decisions, and worse, they are denied the support of the community in terms of a socially endorsed framework of options for their decision-making (Emanuel, 1994). For if no one conception of a meaningful life (and a meaningful death) is superior and there are many such conceptions around, one must either resort to another tool that does favour a conception of the good life or accept all as equally valuable and reduce the life and death decision to an arbitrary one.

A key worry with the principlist approach, then, is that it often oversimplifies the complex, evaluative, and organic nature of social relations. In avoiding difficult questions about meaning in human life and social intervention to advance quality of life, fails to provide sufficient direction and support to those making the decisions.

### ***The challenge for principle-driven approaches***

The articulation and specification of principles is important because it clarifies the various value alternatives that might guide policy decisions (Martin & Singer 2003). It can also help clarify relationships between values and help identify which values are instrumental and which are foundational. For example, in trying to determine whether or not to provide scarce medical resources to dying patients, engaging and testing specific principles can help clarify meanings for the analyst about the importance of saving life, quality of life, and beliefs about death and dying. Nevertheless, in my view, principle-based accounts (both foundationalist and coherentist) face an insurmountable difficulty. The normative challenge to these approaches comes from the fact of diversity and their inability to deal with the reasonable pluralism of modern, liberal, democratic society.

Each of the foundationalist perspectives above offers an answer to the allocation question, can point to its internal consistency and comprehensiveness as an action-guiding theory, and can reasonably suggest that it is the most cogent of the lot. However, they are mutually exclusive. One cannot be both a libertarian and a radical egalitarian. So, in making decisions, one of these principles must be favoured over the others, but which one? Indeed, for each of the principle-based approaches mentioned above there are a variety of interpretations. At the policy level, not only must we decide which principle-based approach is the right one, but we must also choose between different versions, and determine which is the most important. The problem is that this answer cannot be settled. The insoluble difficulty for principle-driven approaches has to do with the inability to reconcile differences between reasonable perspectives about foundational beliefs and values, at the level of practical application to public policy, in a society that endorses the value of democracy. While each principle-driven approach defends a notion of what is right, it has not done so to the satisfaction of all.

Unfortunately, one cannot turn to the principlist method for resolution, because while principlism does allow for the coexistence of prima facie principles that can be derived from different moral theories, it does not offer clear direction for how tensions between these should be resolved. So, principlism effectively pushes the tension between foundational beliefs one step closer to the level of principles. However, the question remains as to which of the principles ought to receive priority in application to the example we have been struggling with – the distribution of a vaccine. Here again, reasonable people might very well disagree. At the level of theory, agreement may not be important. After all, the objective of moral theory is to find truth. At the level of practice, however, one needs to know how and on what basis decisions should be made.

It is for this reason that Norman Daniels (2001) offers the following acknowledgement and change of direction:

> *During the 1980's I became aware that my account of just healthcare, like other general theories, failed to give specific guidance, or gave implausible answers, to certain questions about rationing (Daniels, 1993). Though philosophers may work out middle-level principles that can supplement general accounts of distributive justice and solve these unsolved rationing problems, it is unlikely that there will be consensus on them in the foreseeable future. Distributive issues remain highly contested.*
>
> *In the absence of consensus on distribution principles, we need a fair process to establish legitimacy for critical resource allocation decisions.* (p.2)

Daniels is writing in the narrow context of resource distribution, of which our vaccine question is an example. I wish to broaden this account to system-level decisions in general.

Who is the appropriate moral authority for resolving the differences between competing values in a society where reasonable disagreement persists? In the context of a society that is committed to democratic ideals, the reasoning public is the authority. To be clear, this invocation of democracy is not a conceptual refutation of principle-driven approaches. One of the principle-based approaches may still be the right one. The commitment to democratic ideals is simply a contextually specific fact about our society; however, this fact is relevant in that it articulates the source of moral authority that I believe our society accepts: the rational capacities of its citizens. In part, the strength of the argument that I offer will depend on the nature and extent of the democratic commitments of Canadians. This will be addressed in Chapter Three.

### *Political theory and process-based approaches*

The above concerns about the principle-driven approaches are not meant to dismiss principle-based perspectives. Each of the various approaches above has intuitive appeal on at least some levels, and shades of many of them can be found in existing health care structures and policies – something we will see more clearly in Chapter Three. What we need are processes to help pluralistic societies resolve these differences in the context of public policies in a democratically legitimate way. In short, we need to move from moral theory to political theory and, more specifically, to democratic theory.

The central idea of democracy is that decisions that determine the terms of a collective's association are legitimate to the extent that those affected decide, either directly or through representatives. Moral theory offers many different answers in our vaccine example. Democracy resolves this by turning to those affected to choose. In order to protect against self-interested individuals turning public power to private advantage, democratic legitimacy must be set against constitutionally protected individual rights that, in turn, protect individuals against government and other individuals. To this end, modern, democratic states have created institutions that grant and protect citizens' basic political rights.

Democracy, however, is itself a contested notion with many different interpretations, though most democratic theorists would likely agree with the very general statements above. In the next chapter I compare approaches to democratic theory that focus on balancing the pre-determined interests of members in society with those that seek to transform citizens' perspectives through reasoned discussion and orient decisions toward the public good. I then provide a detailed account of deliberative democracy and apply this to the context of the Canadian healthcare system.

Rather than a theoretically derived starting-point for external justification of the substantive values that should underpin decisions that are made (such as who ought to receive scarce medical resources), I suggest a turn to immanent norms – those values that are embedded within the Canadian health care experience and intrinsic to the way decisions are currently made. In Chapter Three I defend the view among the values of Canadians is a commitment to participatory democracy, particularly in the context of health care. This is the justification for my turn to democracy deliberatively conceived to resolve the difficult questions that regional leaders face.

### Summary

In this chapter, I have described a concept of ethics, and set out the relationships between health care, health policy, ethics, moral theory, and political theory. I have identified a number of different principle-driven approaches to resolving public policy questions in the context of Canadian health care, and offered the critique that incommensurability among these approaches cannot be reconciled or resolved for purposes of policymaking practice. I have suggested that political theory can provide direction on the appropriate process for resolving this dispute for purposes of policymaking on issues such as influenza pandemic planning.

I turn now to democratic theory and the implications of deliberative democratic ideals for system-level decision-making in Canadian health care

# CHAPTER TWO: DELIBERATIVE DEMOCRATIC THEORY

## Introduction

Every day, decisions are made in public health systems about such issues as who will receive scarce influenza vaccinations during a pandemic, where new hospitals will be built and what health services will be provided, whether new treatments for heart patients or more home support for the frail elderly will be resourced, and how no smoking policies will be applied to elderly residents of assisted living facilities. These system-level decisions in Canadian health care are the focus of my research project, which asks: What makes a system-level decision like this legitimate?

A variety of moral theories offer answers to the question of legitimacy – answers that frequently diverge. Moreover, in a pluralistic society citizens can reasonably be expected to have values that not only differ from one another but also may not correspond with moral theories. For such reasons I have turned away from substantive moral theory and towards political theories that look instead to fair processes as the source of justification. These theories propose that, provided a decision is reached by means of a fair process, even members of a community who are disappointed by the decision will accept it. And if they still do not want to accept it, society will be justified in compelling them to do so.

This chapter seeks to define a decision process whose fairness would give democratic legitimacy to a system decision, such as about vaccine allocation. This description will lead towards recommendations that will help leaders in health care develop decision processes able to deliver outcomes that are democratically legitimate. Beginning with pluralist approaches to democracy, I indicate their limitations. Then I examine the process-focused project of Habermas' which provides the starting points for my own analysis. I then detail my approach, specifying the standards and goals of deliberation, who should be involved, how existing social inequality might be addressed, and how actual decisions should reflect public deliberation. The chapter closes with a series of recommendations for leaders in the context of regionalized health care in

Canada. This advice will be incorporated into clusters of recommendations for leaders (offered in Chapter Four) and will inform the theoretical framework for a decision support tool (proposed in Chapter Six).

## Democracy based on public deliberation

In this section I argue that a decision-making process that features free and equal deliberation before voting occurs best honours democratic values and the facts about Canadian society.

### *Why pluralist conceptions of democracy fail*

My analysis shows that pluralist accounts of democracy get facts about society wrong and don't live up to democratic values.

Many liberal democratic theorists favour aggregating individual interests through mechanisms such as voting and elections, and view this as the appropriate standard for democratic legitimacy. These interest-based accounts of political processes and institutions are often responding to an understanding of society as intractably pluralistic. They treat individuals as isolated agents who have pre-formed understandings of their essentially self-regarding preferences. On these views, citizens in their personal lives have previously and individually developed their own understanding of what a good life consists of. They subsequently guide their political participation with a view to securing these pre-defined interests. Politics is therefore understood as the game of securing one's self-interest. Citizens seek to gain their interests not by engaging in democratic discussion but by pursuing those in positions of authority.

In these models of democracy, citizens express their preferences for policies or representatives through mechanisms such as mass voting and opinion polling. These preferences are aggregated, and the result carries the day. The outcome of the process is not seen as the best decision from an impartial perspective, but a function of the strength of influence. The approach purportedly captures the popular will, but this is not reflective of any shared understanding of the common good, but the unintended consequence of collisions of competing interests. In return for being allowed to participate in the process, citizens consent to be governed by the outcomes, whether or not they do take part.

On this approach, the best we can hope for is to elect leaders through mechanisms of voting, set against a strong backbone of constitutional rights that protect citizens equally. Decisions are legitimate to the extent that representatives who have been elected through fair processes make them. Such decisions are regarded as legitimate expressions of the popular will. In the context of Canada's health regions, this argument suggests that decisions about health policy are justified when they are made by leaders who have been delegated this authority by duly elected officials. Thus, for example, an appropriate allocation of vaccines during an influenza pandemic can be justifiably determined by plans representing the values of those in positions of legitimate authority.

There are a number of difficulties with these approaches. For example, such approaches lead to decisions that are not really reflective of public values because they are so removed from the perspectives of the citizenry. Take any decision made at the system-level in Canadian health care (such as vaccine allocation or program level priority-setting) as an example. The public votes to elect members of parliament, the majority of which form a government. The leader then appoints a minister of health. This minister, together with unelected bureaucratic advisors, appoints a board of governors for a health authority. The board hires a Chief Executive Officer. The CEO then hires her staff. It is the staff and CEO that have access to and influence these decisions. These system-level decisions in Canada's representative democracy are thus only thinly guided by the publicly developed values of the Canadian people. A wide range of often competing constraints such as government directives and professional associations do bound the decisions made by leaders. But these do little to improve the democratic nature of the decisions. The Canadian parliamentary system of government is also not designed to hear from those without formal spokespersons (McDonald, 1977). This further undermines the possibility of fair democratic participation, as even formal equality is limited to the election of members of parliament.

A related concern is raised by social choice theorists who object to this pluralist approach by pointing to the inconsistent results that arise using different mechanisms of aggregation (Dryzek, 2000). Starting from the same set of preferences, it has been shown that the different ways in which votes are aggregated lead to different outcomes. Therefore, attempts to characterize the popular will are irretrievably ambiguous. The mechanisms intended to collect and weigh the views of individuals do not offer unquestionable direction on what decisions should be made.

Finally I suggest that such approaches are based on a mistaken understanding of the world and that a more accurate description of social facts demands more participatory approaches to democracy. For example, while society is pluralistic, I suggest that an individual's identity – their understanding of who they are, their value and belief commitments, and what they view as a meaningful life – is not shaped exclusively in the private domain. People develop their understanding of their own interests and the interests of their community through the process of exchanging reasons in the context of social life (Habermas, 1984a&b, Sherwin, 1998). People grow and are shaped in part by the experience of participating in a polity. As well, I suggest that people are not exclusively self-interested. Social interactions are not just manifestations of citizens' privately preconceived and unchangeable notions of what is in their self-interest. Moreover, community interest is often supportive of and not opposed to self-interest. People are, or can be, oriented towards the common good, especially in the context of appropriately structured conversations. And as implied above, appropriately structured conversations can lead to greater understanding between participants about each other's perspectives, shifts in individual perspectives, greater tolerance among the participants for each other, and shifts in position of the participants beyond their own self-interest towards the well-being of the community (Fishkin, 2003, Skogstad, 2003).

If these assumptions are correct, then democratic politics can make room for processes that enable citizens to better understand their own views and through which decisions can be based on more rational, thoughtful, and broadly shared perspectives. In light of this, a strong commitment to the value of democracy as popular sovereignty requires processes that enable to citizens to come together, develop a more rich understanding of what is important to them, and then seek to have policy decisions based on these values.

### *What we can learn from Habermas: Towards a deliberative democracy*

A different approach is offered by deliberative democratic theory, which has grown in part out of the broad philosophical project of Jürgen Habermas. Habermas (1990) developed a moral framework centered on the importance of discourse. Like Kant, Habermas specifies three types of practical reason: pragmatic, ethical, and moral. Ethical reason is about questions of identity, values, and what a meaningful life looks like. For Habermas, people gain their sense of self, their identity, through their participation in networks of reciprocal social relationships. Accordingly, questions of identity and self-understanding for people are rooted in particular cultures and histories. This means that no universal answers to questions of ethics can be provided at the level of philosophical theory.

Habermas focuses then on questions of what makes a decision right or just. This is the domain of moral reason. His goal is to develop a universal conception of justice. He seeks to reconstruct the moral point of view where what is right can be determined fairly and impartially. The idea is to articulate, refine and elaborate basic intuitive moral precepts that are true of any individual participating in a society, irrespective of cultural or historical attribute.

For Habermas, unlike Kant, reason is not a monological and private exercise of abstract reflection, but rather is interactive and communicative, or dialogical (Habermas, 1984b Ch. 5 S.1). Taking a relational understanding of reason and ethics, he argues that it is through communication that we understand each other and ourselves. That is, the truth or rightness of any statement is tied to reasoned agreement about it within a community of actors. When those affected by norms of behaviours come together as free and equal participants and in dialogue come to reasoned agreement about them, we arrive at an understanding of right action. Communication then is itself is a form of moral contract, wherein we engage in dialogue on the promise that contributions to the discussion meet certain standards (Ibid. S.3).

Habermas (1984a) distinguishes between instrumental and communicative rationality. Instrumental rationality seeks to find and implement the best means to achieve pre-defined ends; it focuses on how to achieve goals that have been determined in advance. By contrast, communicative rationality seeks to create understanding between participants in a conversation, where communication is free from coercion, deception, self-deception, strategizing, and manipulation – the ideal speech situation (Habermas, 1995 p.65-66). In communicative rationality, the focus is determining the substantive answer to a question. Ideally, the forum of communication is constructed to allow the decision to be made by collaborative reason, because the desired solution is the one determined by careful, joint consideration, not by influence, reputation, power, intimidation or other such distortions of communication. Ideally, the choice is made by consensus, and the commitment of the participants to the conversation that led to the consensus is what justifies the decision and motivates its acceptance and implementation (Habermas 1984b Ch. 5 S.3).

Deliberative democratic theorists take up the liberal challenge of identifying terms of cooperation acceptable to reasonable but differently situated citizens. Arguing that the pluralism in society is much deeper than traditional liberal theory assumes, they suggest that discussion among citizens (not just plebiscites) is required to justify social policy, and they draw on Habermas' communicative rationality and the concept of the ideal speech situation.[17] The theory of communicative rationality provides a set of standards by which to evaluate the work of existing political institutions (Ibid. Ch. 8 S.3).

Deliberative democratic theory has implications for very broad areas, ranging from state constitutions and public law and policy, to international law, empirical research, and questions of identity and recognition for cultural groups (Chambers, 2003). The goal of deliberative democratic theory is not necessarily to specify in detail just what particular citizen participation forums would be required for democratically legitimate outcomes. Rather, deliberative democrats seek to identify what is required for the ideal to

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[17] Bohman 1996 is a good resource as he sees himself between Rawls and Habermas.

be realized, by characterizing the social conditions that must be in place if collective decisions are to be appropriate.

### *Deliberative approaches to democracy*

The need for policy-making to incorporate meaningful citizen deliberation and for the policy outcomes to reflect the results of this deliberation is becoming widely accepted not only at the level of political theory but also among those directly involved with developing public policy (Dryzek, 2000). The challenge is to specify what "meaningful citizen deliberation" means. In particular, a deliberative democratic theory will have to deal with standards of deliberation, who should be involved, how this should be operationalized, and how to address social facts of inequality and complexity.

Deliberative democratic theory is committed to both respect for individual autonomy and the pursuit of a common good. To balance these values, this approach is committed to the development and support of a public sphere that manifests the values of transparency and deliberative public engagement.[18] There are at least five elements in any complete decision, each of which needs to be carefully considered in an ideal deliberative process. The elements are:

- the identification of an agenda – what issues will be open for discussion;
- the articulation of alternatives for addressing issues;
- the exchange of reasons for and against these alternatives; and
- the selection of an alternative and the making of the decision
- the planning of the implementation and support of decisions.[19]

Elected and appointed leaders in government and government-sponsored organizations must give reasons for the decisions they make on behalf of the people (Gutmann & Thompson, 2004). Members of the polity should actively engage with each other in open dialogue, as free and equal participants, in order to determine the reasons that should under gird public decisions and decision processes. The state must support

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[18] This is a much different approach than that offered in the principlist approach referenced in Chapter One. See again Kotalik 2003.

[19] This last point is often neglected. I argue for its importance in Chapters Three and Four.

institutions that facilitate this dialogue – both within and outside formal decision-making systems. Deliberative democracy is not meant to replace voting to determine law or policy (Chambers, 2003). It is concerned with what happens before voting takes place. It thus sees itself, not as a replacement for representative democracy, but as an expansion of it.

Bohman and Rehg (1997) indicate various lines along which theorists of deliberative democracy may differ. These include:

- Standards of deliberation: Not all types of public engagement are deliberative. Public engagement exercises must meet certain criteria (for example, in balancing freedom and equality) if they are to be considered properly democratic. These criteria are specified by theories of deliberative democracy, which differ in their expectations.
- The goal of decision-making: Deliberative processes differ in their goals. They can strive to achieve consensus, or cooperation, or merely compromise. The goal might be choosing legitimate or justified policy alternatives to an issue, or the answer to the question considered that best approximates justice and truth.
- The roles of different players in the deliberative process: Different approaches will give different roles to discussion in public forums (such as a community council) and public institutions and agencies (such as regional health authorities), and to the connection between these two.

For any decision about vaccine allocation to be justified according to a view of democracy that favours public deliberation, the process by which the guiding values for the decision are determined and the process by which the decision is made must be informed by *citizen participation that meets deliberative standards.* So the questions before us are: what are the right standards in the context of Canada's regionalized health system and how are they to be implemented?

## A model of deliberative democracy for health care in Canada

My model of deliberative democratic theory for health care in Canada calls for an approach to public engagement in decision-making that is decentralized across the country and through communities. The requirement is to build an infrastructure of public engagement that creates many opportunities for participation, each of which is supported with information and education, and to ensure that the deliberative outcomes reached in these are seriously engaged in decisions made.

Earlier I mentioned my assumptions about the formation of individual identity, orientation towards the community, and the impact appropriately structured deliberative forums. In addition to these, my approach is based on beliefs about the pluralistic society and about the capability of individuals to exercise individual autonomy.

I start from the fact that Canadians come from diverse social, cultural, and linguistic backgrounds, living in rural and urban settings, and organized into groups and collectives in myriad ways. Members of society have many different ideas about what constitutes a meaningful life. These include comprehensive theoretical conceptions focusing on substantive principles, some of which will correspond to the principle-based approaches mentioned in Chapter. They also include the much less structured and much more diverse ways of life, traditions, and experiences exhibited in modern, cosmopolitan society. [20] This diversity will have to be addressed in making system-level decisions.

I also accept that people are capable of understanding the information that lies behind the many types of decisions that must be made in modern society. It is sometimes argued that social systems have become too technical and societies too complex for individuals without the proper training and expertise to be able to understand decisions, let alone contribute meaningfully to them. By contrast, my approach argues that with the right kind of support and in appropriately structured conversations, members of society have the skills and knowledge to exercise their autonomy (Fishkin, 1995). There is room for expertise and division of deliberative labour without diminishing the capacity for citizens to exercise meaningful influence and oversight. Of course, if this assumption is incorrect, then deliberation will not yield answers to the problems it seeks to address. Again, these assumptions are empirical claims and, as such, could be evaluated for their accuracy or truth through forms of research.

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[20] See Rawls (1993) discussion on the diversity of comprehensive conceptions of the good.

### ***Standards of deliberation***

Standards of deliberation include resources for individuals (access to decisions, education about decisions, skills of communication) and characteristics of the dialogue (inclusive, reflexive, recursive).

My approach is influenced by the broader deliberative theory of Bohman (1996) who offers a dialogical account of public reason. He sees dialogue as a joint, cooperative social interaction that constitutes the fabric of social life (Ibid. p. 53-57). Bohman likens a polity to a community of actors that have ongoing and fragile relationships with each other. The community is to move forward in determining the terms of its association. This can only happen if the model of public cooperation they use provides reason for all members of the community to continue to participate in the public decision-making process. The key criterion of deliberation is therefore to create a process that will maintain the loyalty and support of participants even when decisions do not go their way. For example, what decision process for vaccine allocation, or any other issue in pandemic planning, would maintain continuing adherence and participation among all those affected?

Bohman suggests that members of the community will find it worthwhile to continue to participate if not so much the particular policy decisions but the reasons for them are acceptable to all (Ibid. p.35). If all members of the community learn the reasons behind decisions, understand these reasons, respond to these reasons, and have their own perspectives understood and responded to in turn, they will accept the decisions that come out of the process. This is sometimes because they agree with the reasoning, sometimes because the discussion has given them a broader understanding of the issues involved, and sometimes because they can foresee these reasons supporting their own positions in future and more important decisions. The importance of reasons for decision has implications for both the resources that members of the community will need and the structure of deliberative conversations.

For such a process to work, individual participants need access to the decision forum where they can hear and be heard, education to be able to understand the issues in question, and support to learn how to express their ideas on the issue effectively. The public should be helped to become aware of the decisions that need to be made and of the complex connections between decisions, and should be supported to understand the relevant technical information on the options. Transparency and public education are thus keys.

This approach is predicated on the values of equality and inclusiveness. Equality refers to the relative power that citizens should have in engaging in deliberative dialogue about the terms of their association (Cohen, 1997). In ideal deliberation, parties would be formally equal, in that the rules of the process would treat everyone with deliberative capacities in the same way, and all would have equal standing at each phase of process (deciding the agenda, proposing and debating options, and making decisions). The parties would also be substantively equal, in that the distribution of power and resources would not have authority in the deliberations, and participants would see the system itself as an object of deliberations. It is the strength of reasons that should guide public decision-making, not power in the form of economic or political standing. Inclusiveness speaks to the reality of inequality in society, and the importance of creating avenues for the participation of those that are excluded from deliberation of public affairs because of their relative powerlessness. The worry that there is unequal allocation of these resources is discussed below.

The focus of this approach is on reasoned decision-making. In ideal deliberation, reasons are required for advancing, supporting, and criticizing proposals. Only "the force of the better argument" (Habermas, 1984a p.25) determines outcomes; threat of physical force, social status, economic status or other forms of coercive power would not. Participants are free in that they are bound only by the results and the preconditions of deliberations, and not by any other pre-commitments (Cohen, 1997). The benefits of reasoned consideration are many (Abelson, Forest, Eyles, Smith, Martin, & Gauvin, 2003). In short, deliberation delivers rational decisions. This is because ideal deliberative processes:

- facilitate the sharing information,

- allow individuals to critically reflect on their own views and better develop an understanding of their own values,
- require publicly stating one's views, which forces one to do so in a manner that others can understand and accept, and
- cause an orientation to a broader point of view or even the common good.

If a decision is reached through a process that approximates ideal deliberation, then because a majority of individuals find the reasons for the decision compelling in light of a reason-driven process, they find the decision to be rationally justified (Bohman, 1996). The public reason-giving process should be inclusive, reflexive, and recursive. It should be inclusive of different types of reasons. It should be reflexive in that it should require an utterer to think carefully about the reasons offered and the audience toward which the reasons are being directed. It should be recursive in that deliberation should be an ongoing process, whereby past decisions can be reconsidered, as can the basic presuppositions of the existing framework of public deliberation.

### *Goals of deliberation*

The basic goal of deliberation should be fair moral compromise, not consensus.

For Bohman, the goal of public deliberation on any issue is the creation of political unity about a genuine moral compromise. Participants are expected to achieve consensus, not on the substantively right answer to a particular issue, but rather on continuing to participate in the process. The object is not to eliminate disagreements in the public sphere. Just the reverse: because disagreements are inevitable and continual, and because they contribute to the growth of the moral community, there is a continuing need to deal with them. So the goal is to have an accepted process for making decisions within a context of disagreements.

In order to address cultural pluralism and respond to these problems, Bohman argues that we need a model of public decision-making that is plural and dynamic. A basic democratic infrastructure must protect political rights and allow for civil society. By plural, Bohman means there must be room in the public deliberative forum for different types of reasons. In contrast to the liberal requirement that there is only one public reason – a neutral, abstract, decontextualized set of reasons that all would agree to – Bohman argues that a multiplicity of reasons can be publicly acceptable and can lead to legitimate outcomes. For Bohman, there is no one single norm of reasonableness.

Bohman's model of publicity is dynamic in that it allows for the engagement of deep conflicts. It neither suppresses, nor neutralizes, nor ignores them, but rather provides room for them in public discussion. This requires a pluralistic notion in that participants will need to recognize that there are multiple legitimate perspectives on any given issue, and that while the set of reasons that carry the day may not be convincing to all, they can be reasonable. This acceptance is what Bohman calls moral compromise, which is made possible on the dialogical model because it allows room for different reasons in the public arena. Bohman suggests that his notion is thus also reflective and inclusive. It is reflective in that it allows, indeed promotes, critical reflection on one's own ideas and the ideas of others. It is inclusive in that it provides room for the ideas of all members of the polity that meet the basic dialogical constraints. In this model, there is room for one's own perspective to be changed in and developed through the participation in the dialogue of the moral space.

Compromise involves access to the dialogical moral space, understanding the reasons of others being given in the moral space, understanding the moral framework of others, and being able to have one's own reasons heard, understood, and engaged in the moral space. While one may not get what one wants, one has reason to feel understood and included as part of the moral space, and to want to continue to be part of the moral space. In this way, citizens are working together to create an expanded framework (the moral space) to discuss the different cultural perspectives that establishes a new moral framework, new rules of cooperation, and new forms of justification that enable continued cooperation.

Moral compromise is fair if it takes into account political inequality, and if there is room for all groups to participate meaningfully in the common moral framework. Accommodating pluralism requires an interpretation of legitimacy in which, rather than dialogue leading to convergence of participants towards a single set of reasons that justify public policy, participants need only to accept the possibility of a diversity of reasonable justifications and to agree that the conditions of deliberation are such that ongoing cooperation with others is worthwhile.

### *Who should participate in a decentred approach*

Ideally all those affected by a given decision or policy, who have deliberative capabilities, and who wish to participate should have access to the processes by which the decision is made. This is based on the value of respect for individual autonomy. But, of course, such a standard is not feasible because of sheer numbers. An alternative is to ensure that a representative sample of the affected population is involved in the decision process. If a group of manageable size could be identified to stand in for the broader community in all its diversity, then the process could be legitimate. There are several difficulties with this option. For example, should representatives be elected or selected? Regardless of how representatives are chosen, difficult decisions will have to be made about matters such as the criteria for candidacy, and whether representatives should reflect the proportional distribution or the equal representation of all different perspectives in a community. Authorization and accountability relationships between those representing and those represented will have to be determined. In order for deliberation to occur, representatives cannot be delegates confined to carry out explicit instructions but rather must be trustees authorized to make decisions on behalf of their constituencies. The process will have to specify how representatives are to account for their actions in the deliberations to the represented community so that the community will feel represented adequately to warrant the continuing participation that is the goal. These challenges do not preclude a representative approach to participation. They do suggest that representation is complicated. The process by which decisions about the selection of representatives and the relationship between representatives and their constituencies will have to meet deliberative criteria.

One worry is that thinking about participation in terms of representation in this way tends to link participation to specific forums of public participation such as a focus group or town hall meetings. The problem is that no matter how well designed and supported such forums are, they will likely remain exposed to criticism as not being appropriately representative. This is particularly true in pluralist societies. Again drawing on Bohman, among others, I suggest that for deliberative decision processes to be legitimate, they must include participation by individuals who represent the affected community, but not necessarily for any single decision (Bohman 1996, Dryzek, 2000). Rather, a variety of moments of deliberative engagement should be included within a broadly conceived public sphere. A variety of decision forums can be included in this sphere, from public hearings and local meetings to citizens' review boards (Bohman, 1996, Abelson, Forest, Eyles, Smith, Martin, & Gauvin, 2002).

Bohman (2004) suggests that such a decentralized understanding of public engagement is *multiperspectival*. It sees members of society as caught up in webs of interaction, and seeks to consider the many perspectives of these members. This approach allows thinking about deep inequalities in political resources. It recognizes that these connections are profoundly uneven, which leads to high risk of the domination of some individuals and calls for democratic processes that makes possible the freedom of all. The multiperspectival polity is not about public self-determination in the sense of common will formation. Rather, it is about non-domination and the norms of accountability and public influence. It is about finding ways of giving those who are disconnected greater access to decision-making processes. The issue of representation then becomes transformed by the notion of a decentralized public with many forums for meetings and discussions.

On my view, then, the deliberative sphere that is to accompany the health care subsystem should not simply be comprised of one-off, ad hoc town meetings where matters are discussed. Rather, we should see the deliberative sphere as a complex undertaking, with many and various forms of public deliberation. Leaders should seek to strengthen the public sphere by identifying areas where domination can occur and finding ways of providing such groups with access to the decision-making process. This requires more than the creation of individual decision forums – it requires a complete reorientation to the deliberative sphere.

### *Nuancing the model in the face of inequality*

New public spaces for deliberation must be created and institutional decision processes need to be reformed to mitigate the social fact of inequality along with the distortions it brings to deliberation.

The social fact of inequality must be addressed in any infrastructure of public engagement. Deliberative democracy requires a public sphere where citizens participate in deliberative dialogue on an equal footing. On this view, the democratic legitimacy of policies is directly related to the extent to which those affected by policies have the ability to initiate public discussion about issues that are of concern to them. But on various morally relevant levels, members of society occupy different and unequal positions. The worry here is that individuals within society are governed by social rules they do not have access to changing (Bohman, 1996). They are included in the polity of the governed, while at the same time publicly excluded. Bohman (Ibid.) identifies three types of inequality that form barriers to decision processes: inequalities of access, of ability to communicate, and of ability to direct the agenda of political discussion and debate.

In order to have one's reasons heard, understood and responded to, one needs to have entry, however indirectly, into the rooms where the decisions are being made. Access to decision-making is an issue when it comes to health system policy-making because the decision-making processes in this context are often vague (Kirby & Simpson, 2007). Only those individuals who have sufficient understanding about the process, groups represented by these individuals, and those directly involved really have access to this policy-making process. Formal inclusion of the public is not enough. As theorists such as Young (2001) suggest, formal inclusion in a context of deep structural inequality only serves to legitimize the interests of those who are socially advantaged by the system. Limiting the transparency of the resource allocation criteria being developed by a regional health board to a discussion of the criteria at a board meeting open to the public does little to honour democratic complexity, even if it formally makes room for public participation in the process. This kind of forum fails to meet the acceptability criterion because it does not provide opportunities for citizens to engage in dialogue with each other, where the reasons of all are heard, understood, and responded to, so that meaningful engagement takes place.

In addition to access, one needs to be able to effectively raise and communicate one's concerns. One could argue that because of the nature of the vernacular that dominates discussion around health system decisions, only those familiar with the administrative culture of health care would be able to have their reasons understood and engaged.

Bohman (1996) understands political power as resources and capacities to influence what decisions are made and in what manner. Without political power, communication can be restricted, and one is still under the power of an authority that one can be denied access to. The political nature of health system decision-making allows for those individuals who are able to win public attention or sympathy for their cause to initiate discussion about issues of relevance to them. However, there exist many groups that are outside the policy-making culture, whose causes are incapable of winning public sentiment, and that lack the skills to get their causes on the radar of the media. For these individuals and groups, popular sovereignty is limited by inequality.

For Young (2001), this gives merit to non-deliberative approaches. I don't disagree with this. That is, there are likely areas where lobbying and protests of various sorts might be well-justified given concerns about inequality. However, as my concern is with the system, I wish to focus on way that public institutions may change to deal with these inequalities. Two main types of remedies are available: the creation of new spaces and the reform of existing spaces.

To create new spaces, Bohman (1996) suggests focusing on improving communication through training, resources, procedures, and opportunities. One way of doing this is to identify and support existing sub-public spaces, where sub-groups of the polity sharing some commonality are able to pool their resources of political deliberation and engage issues on a smaller scale. Rather than seeing these as sources of dissension to be marginalized, a rich and robust deliberative community should nurture these spaces, create new ones, and then find ways of merging these streams into the broader avenues of discussion of social issues. An example of this in the health system is found in Romanow Commission and National Aboriginal Partnership Organization's collaboration on the Aboriginal Forum. This was the main feature of the Romanow Commission's engagement with aboriginal communities.[21]

To reform existing spaces, Bohman (1996) suggests that existing institutions must make room for diverse perspectives, with particular attention to the views of those most politically vulnerable, in order to ensure inclusiveness. When it comes to deliberation on public issues, room for public input from salient perspectives must be made. Which perspectives are salient? This too is a matter of public deliberation, but institutions must ensure that openness prevails, with those who are most vulnerable having access to the agenda setting and the deliberation. These elements themselves must be open to revision when new publics emerge. An example is the inclusion of lay members on ethics committees in the health system.

Bohman (Ibid.) thus argues that the public reason-giving process should be inclusive, with inequalities in the abilities of respective members of the community to participate being identified and addressed.

Ideally, therefore, all those affected by a decision (either directly or through representatives) should have access to the deliberative process. Access should be equal in terms of setting the agenda, of participating in the exchange of reasons for and against alternatives. There should be room to raise for discussion the very norms governing the conversation itself, and past decisions should also be open to review. The process should be inclusive of disempowered perspectives. Participants should expect to have their perspectives meaningfully engaged, and have sufficient confidence in their ability to influence the decision process such that Bohman's test is passed – they feel it is worthwhile to continue in the process. Decisions are legitimate to the extent that they are made in processes that approximate this ideal.

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[21] See Kahane and von Lieres (2007) for a discussion of the engagement with aboriginal people in the Romanow Commission's work.

### *Operationalizing the model in the face of complexity*

Internal decision processes need to clarify the extent to which decisions require the analysis of complicated information requiring experts and the extent to which decisions are made based on values. To the extent that decisions are evaluative, they need to be linked to the public engagement infrastructure.

Good deliberative theory must articulate attainable ideals in light of social facts. But it must also be consistent with democratic self-rule and political equality. A decentralized form of public engagement complicates the link between the output of deliberative forums and actual decisions. If public engagement is diffused in a decentralized public sphere, how should the outcomes of the deliberations within the public sphere inform actual policy making? It is relatively easy to specify a forum of engagement dedicated to a specific policy issue, such as planning for a pandemic: citizens participating in that forum might be empowered to make decisions. But when forums are not specifically connected to issues, how should public engagement influence decision-making? Habermas (1996), Fung (2003), and Bohman (1996) offer three different answers to this question. In preparation for considering these answers, we must examine the complexity of subsystems such as health care.

Modern society needs to be complex to meet social needs, but this complexity creates barriers to meaningful public engagement. As populations grow and society becomes increasingly diverse, there is a corresponding increase in differentiation. Increasingly, complex subsystems are needed to respond to modern social problems, and greater expertise is required to manage these. Predetermined government budgets, developed by experts of one kind or another, are needed to facilitate ongoing social organization. Thus, distinct but interdependent subsystems, such as the government and the economy, with their own internal codes or currencies, are created, and these internal currencies become the determining force in decision-making processes (e.g. votes in the government subsystem and markets in the economic subsystem). Health care, defined earlier as including the areas of public health and medicine, has become such a subsystem. It includes a continually growing scope and specialization of activities with a clear internal hierarchy. In the healthcare context, regional policy-makers are mandated to make decisions, but their choices are bound by government directives, internal bureaucracies, and powerful professional unions, the most powerful being physicians' associations. Does this complexity leave any room for decisions to be made by a deliberative public?

The examples of vaccine distribution and meso-level resource allocation highlight the particular challenges that are posed when the complex subsystems of politics and health care come together. Leaders in the subsystem of politics often do not want to publicly tackle issues that are politically sensitive or unpopular (such as what health care programs not to fund) for fear of losing votes. At the same time, administrators and care providers in positions of authority working in the healthcare subsystem may not want to publicly engage these same questions at the risk of losing their power and control. These internal incentives can create seemingly insuperable barriers to developing deliberative spaces. The issue is complicated by the deep interconnections between the subsystems of politics and health care. Holders of political office want to benefit from giving the Canadian public what it is perceived to want (access to health care), and to do this they exert influence on the priorities of health regions. Yet, in order to avoid the penalties of withholding that which the public is perceived to want, holders of political office download difficult decisions and trade-offs to leaders in the health system. In turn, leaders in the health system turn to the concepts of evidence and effectiveness, because they are motivated variously by wanting to keep their political masters happy (so they can keep their jobs), living up to professional standards of practice (that can be narrowly construed and often unrealistic given resource limitations), and in some cases protecting their type and area of practice. This turn to beliefs and facts (as evidence and effectiveness concern facts about the world, including the consequences of various types of action) becomes a way to avoid talking about values, of which it is feared the explicit engagement will come at some personal cost (Syrett, 2003). This is not to say that discussion of evidence and effectiveness is not important. But what evidence matters and what consequences are desirable are questions of value and as Syrett (Ibid.) suggests a technocratic solution cannot fix an evaluative problem. All of this is not say that leaders cannot have non-selfish motives. Rather, the point is that leaders are in conflict of interest positions that will have to be overcome if the organization is to live up to the commitment to strong public engagement.

In his political theory, Habermas argues that society is too complex to allow a direct linkage between public dialogue and policy-making. Habermas makes an important distinction between "systems" and "lifeworld" (Habermas, 1984b Ch. 6 S.1). The economy and the state are systems. For Habermas, systems in contemporary capitalist, bureaucratized societies are guided by internal imperatives, leading to a focus on instrumental rationality (Ibid. Ch.6 S.2). Steered by the logics of money and power, systems are guided by the principles of efficiency and control. The state is the collection of formal administrative bodies where decisions of law and public policy are officially made. The lifeworld exists outside the state and includes the private sphere as well as civil society – those interactions outside government where efforts are taken to advance the common good. The lifeworld is the process of communicative rationality through which common understandings are reached. Common understandings, including value-commitments, develop through face-to-face interactions over time and in a variety of social groups.

The theory of communicative rationality recognizes the influence of instrumental reason in systems as too strong, and as leading to an overemphasis on technology, science and bureaucracy. The question is therefore how to create conditions for communicative action. Communicative rationality focuses on the public sphere and the possibilities it offers for curbing the oppression inherent in the state (Ibid. Ch. 5 S.3). In this way, it offers a lens through which to examine the state, civil society, and the relationship between the two.

Habermas points out that money and power ultimately rely for their meaning on common understandings and value-commitments. Therefore communicative rationality determines their worth or meaning. Thus, the legitimacy of the system depends on the lifeworld. The real issue is how this public consensus can guide the necessarily complex administrative decisions. For Habermas, public opinion in the lifeworld cannot rule directly because of the complexity of the state system. Democracy is overwhelmed by the constraints on decision-making in the state. These constraints include information and decision costs, asymmetries of competence and expertise, inequalities in access to information, the limits of public attention, and the cultural scarcity of deliberative resources.

Habermas finds the solution in the law and human rights – the basic principles of the democratic constitutional state. The law serves to integrate functions in society and enables deliberation in the lifeworld. Rights constitute and regulate the law-making process. They are elements of a legal order based on mutual recognition and self-regulation. They limit the power of institutions and permit the generation of specifically democratic forms of power. They are the conditions under which it is possible for citizens to collaborate in making law as free and equal citizens. According to Habermas (1996), "informal public opinion formation generates 'influence;' influence is transformed into communicative power through the channels of political elections; and communicative power is again transformed into 'administrative power' through legislation." (p.28)

Habermas (1996) offers a two-track model of deliberative democracy. On this approach, for laws and political decisions to be legitimate, they must be made in institutionalized decision processes that follow two tracks. These processes must both be open to inputs from the informal, unrestricted public sphere, and they must be timely and effective. Habermas connects deliberation, decision-making and the citizenry through a political division of labour. Deliberation is broad, decentred and "subjectless" and is dispersed across the public sphere. It thus potentially involves all citizens. Houses of elected representative leaders are where decision-making legitimately takes place. So Habermas' answer to our question is that we should not try to introduce public deliberation at the complex administrative level but instead should foster it within the public sphere and design institutional procedures that increase the chance that political decisions are based on reasons emerging in the public sphere.

Taking a different approach, Bohman (1996) argues for shifting thinking about institutional design away from traditional focus on legislative processes and towards administrative and bureaucratic structures to make them more deliberative and democratic. He finds that Habermas' separation of public opinion from formal decision-making in the state undermines popular sovereignty and effective public deliberation.

Bohman argues that complexity can be made democratic by linking public engagement to narrow but critical choices. For Bohman, the development of complex subsystems is a necessary and positive development because such subsystems are required to meet society's ends. A differentiated health care system with many areas of specialty, each with its own experts, is indispensable to meet the wide variety of health and illness care needs of the public. The problem arises when, as complex subsystems tend to do, the system treats the public as "objects of control and manipulation," instead of respecting citizens' abilities to understand and inform the decisions that are made about their well-being. (Ibid. 1996 p.189-190) But to argue as Habermas does that complexity and deliberative democracy are irreconcilable is to overstate the degree of complexity required for social functioning. Bohman labels this a problem of hypercomplexity.

The degree of complexity actually required for decisions in complex systems should not be exaggerated. As subsystems become more highly differentiated, they are said to become increasingly specialized and require expert management. This claim takes decision-making control out of the hands of the public and places it in the hands of experts. Bohman argues that in many decisions a high degree of complexity is neither inevitable nor desirable. What is needed is an assessment of the level of technical complexity required to make a decision. Anything more should be avoided (Ibid. p.158-161). Bohman points out that while individual and social freedom may lead to functionally differentiated subsystems, it does not follow that these subsystems are legitimate or ideal. In fact, they may not be legitimate if they did not happen intentionally through processes of public deliberation and decision-making or if they limit public deliberation and decision-making.

The vaccine distribution example demonstrates that complexity does not preclude public engagement. It is certainly true that medical and scientific experts across the world and at local, provincial, national, and international levels who are carrying out surveillance of this virus and of local populations will be required to determine what vaccines will be most useful in what populations under what contexts and in what doses. However, this information alone does not make possible a decision on what groups should be prioritized to receive the vaccine. This will require the application of values. Nor is there any reason why various subgroups of the public cannot gather to deliberate on and offer insight into the values that should determine how these vaccines should be allocated in light of the possible trajectories of the virus. Suggestions that the scientific complexity of influenza prevention somehow precludes deliberative public engagement about vaccine distribution decisions are therefore mistaken.

Bohman argues for "democratic complexity": distribution of the labour of deliberation and decision-making (Ibid. p. 162-164). The level of public input necessary for a given decision may vary from casting a vote to more deliberative inputs. On this account, delegation of policy-making (for example, to administrators or experts in a given situation) is not necessarily anti-egalitarian, depending upon how the role of experts is exercised. For it is true that "most ordinary citizens 'are unable to render medical diagnoses, to test the safety and purity of food and drugs before ingesting them, to conduct structural tests on skyscrapers before entering them, or to make safety checks on elevators, automobiles or airplanes before embarking on them; they must rely on the representations and assessments of experts.'" (Ibid. p.168.) What is important is that the delegation decision about what experts are, and are not, to decide is guided by public deliberation. In this light, delegated decision-making can be democratic if authorized by a public, democratically legitimate process.[22]

Central to Bohman's response is the idea of public trust. According to Bohman, delegation to experts can only be egalitarian when the public has faith that these experts are looking after the public interest. Without this trust, the delegation of decision-making

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[22] In their ethics guidelines for environmental epidemiologists, Soskolne & Light (1996) suggest it is appropriate for scientific experts to advocate for particular positions on issues. However, they argue that experts must "distinguish between scientific and non-scientific considerations" (section 4.2.3). This is an acknowledgment of the need for democratic complexity. It highlights the responsibility on experts to be clear about descriptive evidence about the science behind public policy issues, and the normative dimension about the values that should underpin policy decisions about these issues.

to experts is not legitimate (Ibid. p. 167-170). Moreover, to foster faith in democratic institutions, reputation cannot confer authority: there must be room for the public to challenge experts, expecting them to display their expertise in persuasive explanations. This leads to preservation of equality, because experts must earn the trust of those whom they must convince if their claims are to hold sway. This criterion preserves equality by keeping power in the hands of the public, whose trust must be earned by the experts. At the same time, trusted expert opinion properly presented is vitally important in informing reasons given in public deliberation.

Another practical worry is that because decisions are time-sensitive, and because of the sheer volume of system-level decisions demanded, there is not sufficient opportunity for the public to deliberate on each. This concern can be brandished to lend a coercive tone to public policy development. To this objection Bohman replies that while it is true that decisions often need to be made quickly, these events become coercive only if the routines of policy-making go unreviewed. If there exist sufficient opportunities for participation, review, and revision of certain policies and the policy-making process itself, then time-sensitivity does not necessarily lead to coercion in the longer term or the broader context. Sensitive to Young's (2001) worry, Bohman (1996) observes that the participation-review-revision process can itself become routinized and thereby undemocratic. So, it will be necessary that the democratic complexity of the system be vigilantly reviewed and protected against this ossification of the process.

In summary, Bohman's (1996) approach to complexity is to reconceptualize popular sovereignty so that decision-making authorities and institutions are themselves more deliberative, the interface between the public and the decision-makers is not limited to majority representation, and structured deliberation is not confined to legislative institutions. By his account, what is needed is a collaboration of public deliberation and policy-making to create a deliberative decision-making process where reasons are made public and where all citizens can expect to have their reasons heard and respected, at least so far that they feel it is worthwhile to continue to participate in the process. This way, minorities have a realistic expectation to be heard and to influence the outcomes of decision-making to some extent.

Consistent with Bohman's handling of complexity, Fung (2003) offers a third way of considering the forums of public engagement. He argues that deliberative theorists have mistakenly focused on secondary associations and "plate-tectonic shifts in political and social organization" (Ibid. p.338). Like Bohman, Fung is interested in the public sphere attendant to specific bureaucratic and administrative institutions. But Fung takes a more focused approach, contending that attention should be paid to experiments in the creation of specific "mini-publics" which attempt to manufacture ideal deliberative conditions for relatively small groups. These mini-publics are situations where formal decision authority is given to individuals at a local level to resolve narrowly defined problems. Mechanisms are implemented and supported by broader administrative bodies to enable meaningful deliberation among individuals who share roughly equal power in terms of offering reasons and identifying and evaluating options to address shared issues.

For Fung and Wright (2003), the array of appropriate forums for deliberation should be broadened to include such examples of Empowered Participatory Governance (EPG), because these have the most promise for actualizing the ideals of citizen engagement in a pluralistic polity and also offer important insights into the actual structure and design elements of deliberative forums. In their respective contexts, mini-publics can lead to improvements in public accountability, social justice, effective governance, and popular mobilization.

Fung and Wright identify three general principles that guide the EPG approach (Ibid. p.16-20):

- Practical orientation: the mini-publics seek to address real and specific problems being faced by a community.
- Bottom-up participation: the mini-publics create avenues for the active participation of those most locally affected by the problem – members of the public and local officials – so the process benefits from the knowledge and values of these members.
- Deliberative solution generation: participants engage each other in deliberative dialogue with a view to finding mutually acceptable solutions.

Fung and Wright go on to describe three EPG design features that they hypothesize will meaningfully honour democratic values and allow these to become real and lived (Ibid. p.20-23):

- Devolution: the authority to make decisions for the localized problems engaged is devolved to the mini-public.
- Centralized supervision and coordination: the mini-publics are connected to broader "super-ordinate" bodies which provide resources and support to the local units, facilitate the sharing of learning across local units, and resolve problems beyond the scope of the localized unit.
- State-centred, not voluntaristic: typical decision processes are transformed, and state power and institutions are used to underwrite the deliberative engagement.

According to Fung and Wright, EPG also requires certain background conditions, chief of which is that the participants in the process share roughly equal ability to deliberate together about the issue (Ibid. p.20).

The development in this way of a comprehensive citizen engagement strategy that includes the creation of carefully designed and specified mini-publics can achieve a number of goals. Fung breaks these into four groups. In participation, he suggests mini-publics can improve citizen engagement directly by decreasing the bias of the participants. In improving citizenship, he indicates that mini-publics can provide official decision-makers with relevant information they would not have access to, play an important role in educating the citizenry, and help develop the skills of good citizenship for the participants. In links between citizen engagement and state action, Fung suggests that mini-publics can improve the accountability of officials, a critical issue when there are concerns about poor governance or when there are large gaps between public and governing views. In better policy, mini-publics can also lead to more just policies, through the active inclusion of politically weak groups in the process, and to more effective policies, as those affected by the policies may be more cooperative and compliant from their participation in the policy development process. Overall, Fung and Wright suggest that mini-publics would lead to greater citizen engagement beyond the mini-public exercise – helping to better achieve the overall ideals of democratic government.

As an analogous example, take the "Participatory City Budgeting" project in Porto Alegre, Brazil, as described by Baocchi (2003), whose context has similarities with that of Canada's health regions, including population size, area, and degree of complexity. Porto Alegre is a city of about 3 million people. Though located in a reasonably wealthy state, the city is segregated economically. In 1989, a new participatory structure was developed around the city's municipal budget that brought it under popular control. The new process happens over a yearly cycle, and includes a two-tiered structure of forums, wherein citizens participate both as citizens and as representatives of civil society groups. The process includes regional assemblies that bring together members of local communities (sometimes in the thousands), both to review budgets and projects and to elect regional representatives. Delegates then meet regularly to learn about projects and deliberate about local needs. A second round of regional assemblies is then held, in order to vote on the regional district's respective priorities and to elect representatives to a smaller municipal council of the budget. This council then meets with municipal government officials over several months to reconcile the priorities of different districts, propose and approve the budget, and amend the scope and rules of the process itself.

The Porto Alegre process has a number of features that enable it to live up to deliberative democratic standards. First, it involves the direct deliberation of local citizens. Second, it empowers local populations to make decisions. Its work is supported and coordinated by the central government, but the decisional authority of the process is respected. It also includes citizen reflection on the decision process itself. Baocchi (Ibid.) suggests that a number of favourable outcomes have resulted from the experience. The municipal budget is perceived to have greater legitimacy. There have been increasing levels of engagement with the process, particularly from members of less affluent communities. The needs of vulnerable populations have been better met. The process has been effective, serving the needs of the city, while increasing the amount of the budget available for investment. The experience has been so positive that the process has been expanded to include other areas, ranging from social and health services to sports and education.

For our purposes, the Porto Alegre example shows how meaningful citizen engagement can successfully serve a significantly complex system that serves a large population.

This analysis helps us move towards a clearer answer to the question of empowerment: How far should leaders be beholden to the outcomes of deliberative processes in the public sphere? For example, have leaders lived up to the demands of democratic legitimacy if they take these outcomes into account in their own deliberations and respond to them explicitly, but in their practical decisions seem to deviate from them or even contradict them without explanation?

Bohman (1996) shows that institutional decision-making can be informed by a public sphere and still maintain the degree of complexity necessary to meet social goals. Fung (2003) and Fung and Wright (2003) provide a theoretical model for what such a public sphere might look like and offers an example of a working mini-public. In my view then, leaders in the health system should create citizen assemblies as part of the public sphere to surround the healthcare system. If the citizen assemblies created take the form of mini-publics, then as shown by the Porto Alegre budgeting experience, these can successfully be empowered with decisional authority on the principles of the Empowered Participatory Governance model described by Fung and Wright (2003) – and they should be so empowered. If leaders respect the public sphere but take a decentralized view of it, then individual forums of engagement need not be empowered, but decision-makers should be accountable to them in the sense that they should provide participants with the decisions made about which the forum was gathered, the rationale for these decisions, including value trade-offs required, and how the reasons in the output of the forum were taken into consideration and responded to. If a public sphere is created that meets the values of democracy deliberatively conceived, then decisions will be legitimate that are directly guided by its outputs. The less these ideals are met by decision-makers, the less empowered will be the public sphere, however effective it is as a deliberative forum.

This concept appears to create an incentive for leaders in the system not to nurture the public sphere, because the less effective it is the more power remains in their hands.

This may be true in a narrow sense of leader self-interest. And yet the same leader will also have a broader, longer-term interest in heading a successful operation that has notable accomplishments and a reputation for effectiveness. This chapter has tried to show that such higher-level, longer-term institutional success is linked to how well the ideals of deliberative democracy are met, to how effective and widely accepted are the decisions reached. The stronger the team, the better the leader looks. In this light, the deepest incentive for a leader is to share power effectively with a highly enabled public sphere. Leaders will come to realize that their own empowerment reflects that of the public sphere they serve and those accomplishments are most durable which realize ideal deliberative engagements.

## How to improve system-level decision-making

Having reviewed deliberative democratic theory, can we spell out what it recommends for system-level decisions made by leaders in Canada's regional health authorities? How can these leaders strengthen the public sphere and make it an effective partner in reaching good decisions?

The advice to regional health leaders comes in four areas: The importance of democratically justified decisions; changes that leaders can make to their internal decision processes immediately; the nurturing of a public sphere; and an understanding of the characteristics an enabled public sphere. These areas are further elaborated in the decision-support instrument developed later in this dissertation.

### *The importance of democratically justified decisions*

As elites in positions of authority whose decisions are rarely visible, let alone questioned, regional health leaders and their teams may not yet recognize the value content of their decisions, or the fragile moral authority they have to make the decisions in their mandate. Leaders should reflect on how the decisions they make are value-laden, and how the values that guide these decisions need to be publicly established in a way that makes them more than their own subjective prejudices.

Leaders would benefit from reflective dialogue about the extent and potential bias imparted by their subjective assumptions and opinions. They will be helped in this task by considering the social facts of pluralism in their region and in Canada as a whole, the capacity and right of ordinary citizens to participate in decisions, the influences exercised by ethnic and community identities and interests, and by the practical efficacy of meaningful dialogue. Leaders should also consider what is entailed by democracy, citizenship, equality, inclusiveness, and trust.

This chapter has explained the connections between accountability, legitimacy, and deliberative democratic processes. Leaders should understand that they could build trust and support by openly seeking accountability through decisions that explicitly and demonstrably are guided by values chosen and proclaimed through deliberative processes. Instead of hiding their decision-making behind claims of complexity, they should do their utmost to show how complexity is subordinate to and guided by public values. In short, leaders can act in ways to turn deliberative processes from opponents into allies.

A leader positioned as a trusted ally of deliberative processes will find it easy to explain and support the roles of experts in scientifically complex issues and of elites in politically complex decisions. Once public trust is firmly established, both aspirationally and practically, the leader will find system-level decisions much less subject to criticism. System-level decision processes will be more easily accepted because they are justified as instruments of a higher and more authoritative public scrutiny and engagement.

A leader in this fortunate position, understanding the deliberative basis of his legitimacy, will pay close and continuing attention to issues of pluralism and inequality. Regional leaders will find themselves the strongest advocates of a deep and broadly effective public sphere. They will see it as taking many forms beyond the conventional town hall meeting. The public sphere should be expanded to include broad structures of public engagement: formal, public decision-making authorities, work in associations and existing groupings in civil society, and the kinds of mini-publics that Fung and Wright (2003) outline. Leaders will recognize that citizens face inequalities in accessing the public sphere, some of which are deeply structural, taking the form of biases in certain discourse and forms of communication. Astute leaders will understand that these inequalities threaten their own legitimacy. They will seek to understand how and where political domination occurs, and will look for ways to overcome this domination, in order to create genuine equality and inclusiveness in the public sphere that supports them.

### *Immediate practical actions*

Beyond the reflective philosophical and strategic work of developing and understanding justified decisions, there are a number of practical measures that leadership teams can take in the present context to reform their institutions and internal decision processes in order to create and enforce the conditions for ideal public deliberation.

Leadership must learn, and then clarify, the extent to which the decisions they encounter involve values that the public has a right to understand and decide. To that extent, in making a decision the leaders are acting on behalf of the public. Since every decision in the health field can easily be shown to have ethical implications, the task is not to understand *which* decisions are value-laden but rather to identify the value dimensions in each decision. What's more, the task is to identify the value trade-offs involved in choosing between options. The purpose of this task is to make public the value trade-offs at stake in the decision. At this point, especially, leaders will become aware of the benefit to be gained from the support of appropriate deliberative processes.

Honouring pluralism as a value, and recognizing pluralism and inequality as facts about society, leaders will have to strive to exhibit ideal deliberative procedures in their own decision processes. Leaders should seek to demonstrate the values of inclusiveness (of different styles of thinking), equality, pluralism, reflexivity (awareness of audience values), and recursiveness (openness to review of earlier decisions). They should try to ensure that decisions are reason-driven and thoughtful, and not based on power dynamics, bargaining, and horse-trading. The processes should enable leader-deliberators to share their reasons for action, hear the reasons of others, and engage each other about these reasons, with a view to developing a shared approach to the issue, whereby all perspectives are fully honoured and participants are able to live with decisions made.

In other words, the decision-making processes should allow the decision-makers to reflect on their own perspectives, understand their value commitments, and engage each other such that value commitments may change. These processes should formally consider and engage different value perspectives in their deliberations. Wherever possible, they should allow different perspectives to be presented by those who hold them. A useful guide might be an altered form of Young's test of inclusion: if a decision concerns a segment of the population that is not represented by the deliberators, whose perspectives deliberators cannot meaningfully relate to, and who have little power to hold decision-makers accountable for their decisions, then this group is effectively excluded from the decision process, and leaders should create an avenue for their perspective to be directly heard and engaged. The process should enable leaders to openly question the very framework used to review past decisions.

Finally, when a decision is made, its content and the reasons for it should be made meaningfully transparent to the public. The reasons provided should include the explicit responses of decision-makers to the various perspectives considered and engaged.

### ***Nurturing the public sphere***

Changing the understanding, culture, and standards of internal decision practices, though vital, will only go so far towards meeting the requirements of deliberative democratic theory. Beyond greater transparency, the health region, through its leadership, will have to actively support deliberative practices in the community and seek to build a political public sphere around it. This effort will need to go beyond the veneer public participation. Given the absence of the public sphere as concerns the health care system, it will need to involve:

- the creation of new deliberative processes within the public sphere;
- the identification and refashioning of existing forums where these might exist to make them more deliberative; and
- exploring areas where affected parties do not have access to decision processes and actively seeking to overcome this alienation by means of both strategies above.

The task of nurturing public engagement demands short-term and long-term methods. A deliberative democratic standard for decision-making represents an enormous change that can only happen gradually and in steps. Accordingly, it will be useful for leaders to distinguish immediate measures from others that will become appropriate as democratization proceeds.

### *Characteristics of an enabled public sphere*

In developing new forums of engagement and helping existing forums become more deliberative, a health region should strive to demonstrate the following characteristics in the public sphere that surrounds it. The recommendations are complementary and sometimes respond to more than one of the challenges. This list effectively represents a checklist against which the quality of the public sphere can be evaluated.

Responding to challenges of complexity:

- Participants should have enough confidence in their ability to influence the decision process that they feel it worthwhile to continue participating.
- The public should have access to the types of complex decisions that need to be regularly made.
- Through adequate explanations, the public should be supported in developing an understanding of the relevant information needed to make such decisions.
- Participants should expect to have their perspectives meaningfully engaged.
- To the extent that a mini-public is able to meet Fung and Wright's standards of empowered participatory governance as outlined above, these mini-publics should be empowered with the authority to make decisions.

Responding to challenges of pluralism:

- Deliberative processes should treat different voices with respect, so that the reasons of all can be heard, understood, and responded to.
- There should be opportunity to review and revise past decisions.
- There should be room for all types of reasons to be engaged, including dogmatic perspectives that holders are unlikely to change.
- The approach should always be to seek solutions that respect a broad range of value perspectives and the conditions for fair, moral compromise.

- Fundamental disagreements – deep conflicts – should be handled with mutual respect, and the goal should be to identify and continue to meaningfully engage these, even as time-sensitive decisions must be made.
- There should be room to question the assumptions behind decisions and the conceptual framework within which decisions are being made, challenging prevailing discourses. Changing the agenda and revising the questions should be possible.
- There should be intentional consideration of what forms of expression are acceptable, and room for different types of communication should be ensured.
- To the extent that the public sphere is seen as decentralized, leaders should engage the reasons delivered by these moments of engagement elsewhere, and respond to them in their own decisions.

Responding to challenges of inequality:

- The mandate of the facilitators of the public sphere should include an intentional effort to identify where political domination occurs, and find ways to increase access to the deliberative sphere and empower the excluded populations. In particular, when such groups are identified, leaders should:
    - Focus on the capacity of such individuals to use resources, procedures and opportunities for effective communication.
    - Find ways to provide such groups with access to the decision-making process, either by creating new deliberative public spaces or reshaping existing ones.
    - Identify and support existing sub-public spaces – spaces where sub-groups of the polity sharing some commonality can pool their resources of political deliberation and engage issues on a smaller scale.
    - Avoid dismissing excluded groups as sources of dissension to be marginalized, but instead seek to nurture their spaces and find ways of merging these streams into the broader avenues of discussion of social issues.
    - Young's (1999) test for inclusion should be adopted. Again, this test requires that

> *If a public debate usually refers to a social segment in the third person, if that social segment rarely if ever appears as a group to whom deliberators appeal, and if there are few signs that public participants in deliberation believe themselves accountable to that social segment, among others, then that social segment has almost certainly been excluded from deliberations.* (P.157)

To readers familiar with the regionalized health care context in Canada, the foregoing set of criteria for deliberative legitimacy will seem like a very tall order – and indeed it is. Genuinely justified decisions will require a reorientation of the deliberative sphere.

Nevertheless, these recommendations are translated into a toolkit, which will be presented and discussed later in this dissertation. Furthermore, Chapter Four below offers a practical prescription for steps that, if taken, would move us closer to the ideal articulated here. The prescription sets a high bar, but is reasonable in the current context. It is very important to be clear that while the small steps later proposed may offer more workable solutions, justified decision-making at the system-level really does require achieving the standards laid out in this chapter.

The feasibility of all this is increased by Canada's commitment to democratic ideals, deliberately conceived. The next chapter explores the considerable substantive and procedural commitments Canadians have made in their thinking about health care and the development of the existing system. In light of these commitments and developments, the deliberative approaches discussed and recommended here simply work to move institutional developments forward to their natural completion.

# CHAPTER THREE: IMMANENT VALUES IN CANADIAN HEALTH CARE

## Introduction

In my effort to articulate standards of justification for system-level decisions in Canadian health care, there are three areas that remain to be addressed:

- The value that Canadians actually attach to participatory democracy,
- Direction for leaders on the substantive values that should inform their decisions as the robust public sphere that I am advocating develops, and
- A set of considerations to serve as starting points in the framing of issues and questions for presentation in the public sphere.

I begin this chapter by describing these missing pieces in more detail and framing the challenges attached with the method of literature review to try and consolidate the values of Canadians. I then provide an overview of the sources for Canadian values on which my analysis relies. After this I draw what I take to be the strongest principled commitments that Canadians seem to share around health care. For each I indicate reasons why I believe Canadians take the value seriously and what these commitments imply. Finally, I suggest what leaders at the meso-level in Canada's health system could do in order to meaningfully live up to these values, beyond using these as criteria by which to judge system-level decisions.

## On Identifying Values

### *The need for descriptive evidence of Canadians' values*

There are three important reasons to critically reflect on the values of Canadians.

In Chapter Two I argued for a notion of democracy for the Canadian healthcare context that features the deliberative engagement of the public, who, ideally, are empowered to make decisions. This assumes that Canadians are committed to the values associated with participatory democracy in this context. A central reason for considering what is important to Canadians is examining the alignment of their descriptive values with the normative account I defend. In democratic societies, when reasonable differences about substantive normative principles exist, moral authority for resolving disagreements rests with the people – those affected by the decisions. The public can choose to delegate this authority to representatives or experts. Or it can exercise this authority directly in the form of increased citizen participation or even direct democracy (Skogstad, 2003). If there is close alignment between the commitment of the Canadian public to greater participatory democracy in the healthcare context and the deliberative democratic ideal I defend, then the normative standards that come out of Chapter Two are strengthened. If the commitment is weak, then the standards are less compelling. In this chapter, I provide evidence that establishes such a commitment.

Second, little infrastructure is currently in place at the level of the health region, conceptually or institutionally, to facilitate the degree of public engagement required to meet standards of justification set out so far (Abelson, Forest, Eyles, Smith, Martin, & Gauvin, 2002). And this likely will be the case for some time. But decisions need to be made immediately – an influenza pandemic, for example, may come at any time so pandemic planning cannot wait. I argued in Chapter One that ethical justification is not black or white, but rather admits of degrees. The question is, until the public sphere is established, how can the decisions made by leaders maximize the degree of justification possible given current arrangements? I argued in Chapter Two and will detail further in Chapter Four that leaders can begin to take steps in the desired direction by reorganizing their internal decision processes and making these and the decisions themselves as transparent as possible. Here I suggest that understanding the substantive values of Canadians and ensuring that these are addressed in the decisions that leaders currently make also contributes to their legitimacy. These are justified for use in the short-term by their grounding in Canadian perspectives (to the extent that the grounding analysis is accurate) and by their application within and against a broader deliberative project.

Third, as we move towards this procedural approach to system-level decision-making that emphasizes deliberation, we will need a place to start. As this will happen against a context already rich with conceptions of the right and the good, these notions should inform decision processes as the starting points for value discussions, to be tested and corrected within deliberative forums.

### ***Sources of understanding***

In identifying key values Canadians hold dear, I turn to several key sources. These include a) the findings of the Values Working Group of the National Forum on Health (NFH) which published in 1997 the findings of its qualitative research into the values of Canadians; b) a paper by Mendelsohn (2002) that evaluates extensive polling data available on the values of Canadians around health care, focusing especially on the period after 1996; c) the fact of the Canadian health system, including current federal legislation (primarily the *Canada Health Act*, unanimously passed in 1984 (Health Canada, 2002)) and the history of its development; and d) a paper prepared by Fooks and Lewis (2002) summarizing key areas of agreement and tension in the various federal and provincial reports on Canadian health reform. I also consider various additional articles and books in the literature on Canadian values around health care. The following is a brief summary of these resources and their methods of analyses.

### ***The National Forum on Health***

The National Forum on Health (1997) formed a working group on values to understand the views of Canadians on issues facing the Canadian health system. This national group saw itself as a demonstration "of the values of dialogue, participation, and respectful listening" (Introduction section, para. 4). The group first developed a number of scenarios that captured the tensions in the health system and then embarked on a qualitative and quantitative research project to evaluate what was important to Canadians in these situations. The group conducted eighteen focus groups and surveyed 800 individuals from across the country. They also commissioned a review of national and international ethics groups' work with these issues. This effort aimed to ensure that "Canadians know that their values have been heard and understood by the forum" (Ibid. para. 5). The working group distinguished between "surface opinions" and "deep, beneath-the-surface convictions" or values (Ibid. para. 6). Surface opinions were defined as those made with little understanding of the situation and little time and energy spent thinking about it. Values were defined as "stable cultural propositions about what is deemed to be good or bad by a society" (Ibid. para. 7). The working group believed that it was able to identify a number of values common to most Canadians as concern the healthcare system.

## ***Mendelsohn Report on Polling Data***

Mendelsohn (2002) prepared "Canadians Thoughts on Their Health System: Preserving the Canadian Model Through Innovation" as a submission to the Commission on the Future of Health Care in Canada (CFHCC), led by Roy Romanow (2002). He identified over 100 polls conducted since 1985, including over 1000 questions relevant to Canadians' thoughts about their healthcare system. From these, he chose "those most representative and that best highlighted the general trends and state of Canadian public opinion" (Mendelsohn, 2002 p. 1). Sources of information for the report included the Parliamentary Library (housing surveys commissioned by the government of Canada), the Canadian Opinion Research Archive at Queens University, and Canada's major polling firms. Mendelsohn distinguishes between public opinion and public judgment. He defines public opinion as "off-the-cuff, transitory responses to recent events" (Ibid. p.1). In contrast, he refers to public judgment as the "informed and relatively stable preferences that reflect people's deeply held views" (Ibid. p.2). Mendelsohn argues that Canadians have reached a "mature, settled public judgment, based on decades of experience" about their healthcare system. He suggests that his report captures and reflects this public judgment (Ibid. p.1).

## ***Fooks' and Lewis' Summary of Canadian Health Reform Reports***

Recently there have been a number of commissioned reports on health reform in Canada. In their paper, Fooks and Lewis (2002) consider five provincial reports and three national reports to identify emerging themes in Canadian health reform along with areas of agreement and tension amongst these. The provincial reports considered include work done in Alberta, Saskatchewan, Ontario, Quebec, and New Brunswick. The national reports include the National Forum on Health, the Senate Committee, and the Interim Report from the Romanow Commission. Fooks and Lewis' report does not focus on values. Rather it identifies a number of themes (nine) that are common to each of these reports. Each of these themes suggests values in common and in tension, and the report does articulate the major value commitments that are suggested by the various reports studied.

## ***Health System Structure including the Canada Health Act and Events Leading to Its Creation***

The *Canada Health Act* and Canadian history leading up to the present day healthcare system demonstrates the values of Canadians. DiMarco and Storch (1995) suggest that, "[Canadian social] values have been immensely important for developing a healthcare system designed for the common good" (p.5). This history is marked by interplay of special interests, civil society, the public at large and both provincial and federal governments. It includes events such as strikes by professional bodies and the creation and amendment of provincial and federal legislation. It is a history marked by cycles of tension, shared understanding and agreement, and then contestation again.[23]

### ***Articulating Canadian Values: A Fool's Errand?***

Although an attempt to summarize the values of a diverse population through a review of the literature may be seen as a fools' errand, such an analysis of Canadians' values about their health system yields an understanding of values that can be used as starting points in decision processes.

The general concern with trying to determine a group's values through document analysis is that it does not allow the population to speak for itself. In Chapter Two I argued that for an understanding to legitimately describe a group's perspective, it needs to meet standards of deliberation that include the freedom to set the agenda of discussion and to engage in deliberative dialogue. Otherwise, concerns about inequality and aggregation suggest the outcomes do not legitimately reflect the will of those involved.[24]

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[23] A brief summary of this history, drawn largely from analyses done by the Canadian Bar Association (1994) and DiMarco and Storch (1995) is provided in the Appendix A.

[24] Questions about inequality range from who had access to the forums of input in the reports written to the discourses embedded in the questions the report chose to ask. For example, while the National Forum on Health's Values Working Group aimed to meet standards of deliberation in their focus groups, it indicates that only ten of the eighteen focus groups conducted met these standards. It is silent on

The general worry of this method includes the suspicion that such a "meta-analysis" as I am attempting of various reports that themselves seek to summarize certain value themes is deeply subjective. The concern is that any findings I come up with are based on my evaluative analysis of other researchers' evaluative analyses – all of which is many times removed from the actual views of the people about whom something is being said.

Giacomini, Hurley, Gold, Smith, and Abelson (2004) also raise three specific concerns about any analysis of reports that concern values in the healthcare context. Their work is based on an analysis of 36 reports about health reform in Canada. First, while

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what these standards are, what values informed or were implicit in the discourse of the stories around which discussion in the focus groups was framed, and whether participants had room to alter the agenda and the focus of the conversation. Worries about aggregation have to do with skepticism about whether the consensual views of a group can actually be provided by quantitative research methods. For example, Mendelsohn's research relied exclusively on reviewing surveys. But social choice theorists question the reliability of results as the way results are aggregated can lead to different conclusions.

values are generally seen as very important (as demonstrated by the comment on this in various health reform documents) there is considerable disagreement about what values are. Reports were found to identify as values things from five different ontological categories: goodness (e.g. quality and effectiveness), physical entities (e.g. specific programs and services), principles (e.g. equity), specific goals (e.g. illness prevention), and attitudes (e.g. compassion). This diversity of language can lead to people speaking at cross-purposes. For example, how is one to weigh and compare such different things as prevention and compassion, as one study tries to do? This makes any values analysis of a single report or between reports suspect.

Second, Giacomini et al. (Ibid.) found that while all the reports they considered named certain specific values as important, others were not declared. It was not clear how a report's silence about a value should be interpreted. Did the authors believe it was important but politically inexpedient to raise it? Is absence an indication that the value is not important? Does it suggest that the value was so important and obvious as to go without saying? Or was it part of a bundle of values that are implicit within the values described? The point here is that any analysis of values requires a deep sensitivity and attention to the context within which the report was developed. "Interpreting a missing value requires a sophisticated understanding of the context (in particular, what everyone *else* is talking about at any historical moment) and the authors' intentions." (Ibid. p.21; italics in original.)

Finally, the values articulated by a given report did not always match the recommendations of the report. The work of the values articulated in reports ranged from "structural foundation to window dressing" (Ibid. p.20). This suggests that if what is important to the authors is of interest, it may be the recommendations of the report that really capture this, not the values that the report formally names.

These specific worries suggest that without sufficient understanding of the context within which the reports I seek to consider were developed, and without a clear understanding of my own intentions and value-commitments, my values analysis will be suspect. So am I a fool to undertake the exercise of identifying key value commitments of

Canadians? I don't believe so. I acknowledge that the exercise of identifying Canadians values through literature review is problematic. However, the problems do not stand in the way of achieving my stated objective of approximating what is important to Canadians, including their commitment to participatory democracy. My goal is not to define the values of Canadians once and for all. Rather, I seek a sufficiently plausible account of what is important to Canadians a) to justify opening discussion of system-level decisions to public deliberation; b) to have leaders take these values seriously in their consideration of system-level decisions in the absence of a public sphere surrounding to the health system; and c) that can be used as a starting point in public deliberations.

There is certainly disagreement and tension amongst Canadians with respect to what is important to them in their health system. But I submit that if the values that define a Canadian identity are a painting, though nowhere near resembling a crisp photograph, it is closer to an impressionistic portrait than a work of abstract expressionism. There is a discernable image when viewed from a distance, even if the lines blur on finer examination. While I believe the values of Canadians do emerge, their implications have not yet been fully anticipated or reflected in health system decision-making. That is, not only are there tensions between different values when it comes to system decisions in health care, but there are inconsistencies in the way these values are lived. So while certain values have in effect won out (for now), they are not consistently reflected in the existing healthcare infrastructure. I hope that this critical reflection on the values that do underpin health system decision-making will advance how decision-makers in particular think about values in system-level decision-making.

## Immanent Values

Now I turn to what I believe are values immanent in the Canadian healthcare context. In Chapter One we saw that principle-driven approaches cannot deal adequately with pluralism. However, this isn't to say that our thinking about healthcare allocation isn't importantly driven by shared values and principles. Canadians have thought about, and been consulted on, their values in the context of health care a great deal. And while there have been values in tension over the history of the development and evolution of Canada's health system, several key values have emerged as central to the concern of Canadians. In my view, these values are:

- Participatory democracy and health care as a symbol of Canadian identity
- Accountability, good governance and responsible stewardship of public resources
- Healthcare provider integrity and accountability
- Solidarity, compassion, and equitable access based on need
- Effectiveness: access to a comprehensive set of high quality services

Three of these five values are process values. That is, participatory democracy, accountability, and health care provider integrity have implications for the way decisions are made. The remaining two, equitable access and comprehensive quality services are substantive values. They concern the actual content of decisions. The distinction will impact the way that these values are realized in decision-making.

### ***Participatory democracy and health care as a symbol of Canadian identity***

There is reason to believe that Canadians value the idea of participatory democracy when it comes to health care. This evidence is direct, in the form of Canadians' explicit value commitments to participating in health system decision-making and as an expression of Canadian identity. It is also found indirectly, in explicit value commitments around governance and accountability. I explore the direct evidence about Canadians' democratic commitments in this section and the indirect evidence in the following section.

Canada is not built on the values of participatory democracy (McDonald, 1977). As a parliamentary democracy it formally assigns decision authority for governance of public affairs with elected representatives (Skogstad, 2003). However, a shift has been detected in the overall democratic ideals of Canadians from a commitment to elite driven decision-making towards greater participatory democracy (Nevitte, 1996). There is evidence to suggest that at least four conceptions of political authority (to elites, experts, the market, and citizens themselves) exist in Canada and appropriate deference to authority for Canadians' is sector specific (McDonald, 1977, Skogstad, 2003). There is good reason to think that Canadians increasingly wish greater influence and involvement in decision-making about their health system.

The NFH Values Working Group (1997) named mechanisms for assisting Canadians to think seriously and critically on their values and providing this input to policy decision-makers as something of importance to Canadians. The value of "collective responsibility" is described in terms of public engagement in decision-making:

> *People want to participate meaningfully in decisions about their own health system. Representation on community or regional boards and participation in community needs assessments are two forms of participation. Greater public involvement at a community level will ensure that needs and values of different cultural, linguistic and religious groups will be represented and upheld. Public participation is facilitated when sound accurate information is readily available, to ensure the system is accountable.* (Collective responsibility section, para. 1)

Mendelsohn's report (2002) does not name citizen participation as a key value directly. The one directly relevant poll on this topic asked: "Who should play a lead role in setting policies to protect patients and ensure best care?" (p. 82.) 67% percent of respondents suggested that the public should play a lead (30%) or significant (37%) role. As well, by virtue of participation of the public in the polls and the passionate responses received, there seems to be an implicit suggestion in the report that this is important.

In terms of health system structure, it is acknowledged that one of the important reasons behind the shift towards regionalized health systems across the country is that this structure is meant to improve citizen participation (Lomas, 1997, Lomas, Woods, & Veenstra, 1997a-c). Dickinson (2002) argues that this move was designed intentionally to help create the political climate needed to move away from medical expert (physician) driven decision-making of the Medicare system. Government consultations on the values of Canadians about the health system have occurred at the federal, provincial, and local levels. Each is a demonstration of the importance of public engagement. As the Values Working Group report suggests, "the National Forum on Health is in itself an expression of the importance of the values of dialogue, participation and respectful listening" (Introduction section, para. 4).

At the federal level a public consultation website lists 100 closed, 11 current, and 1 future consultation on a variety of health topics (Health Canada, 2008). An important example of commitment at the national level to meaningful citizen engagement comes from the Commission on the Future of Health Care in Canada referred to as the Romanow Report – *Building on Values: The Future of Health Care in Canada* (CFHCC, 2002, Maxwell, Jackson, Legowski, Roswell, & Yankelovich, 2002, Maxwell & Fooks, 2002). The project included 12 one-day public 'deliberative dialogue' sessions with 40 randomly selected Canadians; a televised forum on six themes: values, sustainability, resources, access, principles, innovation – with telephone lines open for comments after each session; 21 days of open public forums; expert workshops in nine communities to ask participants to assist in interpreting the results of the former sessions; three regional forums to further engage the community and gauge the extent of consensus across the regions; partnered dialogue sessions to broaden public awareness and engage expert and academic communities; nine issue survey papers in partnership with Canadian Health Services Research Foundation; a consultation workbook "Shape the Future of Health Care"; site visits and meeting with National Forum and National Caucus to get stakeholder perspectives and to give materials to be shared with constituents; and a variety of speeches and presentations held to inform stakeholder and other groups.

At the provincial and local levels there have also been a number of exercises in public engagement,[25] but whether these aimed at meeting deliberative standards, and if so, how well these were achieved it is not clear. For example, the British Columbia Ministry of Health recently completed what it calls the Conversation on Health (BC Ministry of Health, 2007). This year-long engagement process included 16 community forums, public consultations held by local health agencies and facilities intended to provide a similar forum, as well as input on the Ministry of Health website, individual

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[25] The Province of Alberta hosted several public engagement Health Summits from 1999 to 2002 on the future directions for the health system. The Province of Saskatchewan hosted Citizens Round Table discussions to deal with health care cuts from 93-94 and also initiated a public consultation series in 1997. In Manitoba, a Public Consultation series was hosted in 2001. Public forums were held by Manitoba Health in January 2002 in Brandon, Thompson and Winnipeg and approximately 430 individuals participated. And in Ontario, a Public Consultation on the Future of Health Care is currently being held. (Health Canada, 2008).

submissions and correspondence through an electronic message board. The process of engagement in this conversation was varied, though some structural elements met standards of deliberative engagement. For example, the agenda for the 16 public meetings was left very much up to the participants. Overall, the structural arrangements for this conversation were not deliberative. They aimed at hearing and thematizing the pre-formed perspectives of British Columbians, but not necessarily facilitating engagement among different voices. An interesting finding in the report on the Conversation is that many participants offered critical feedback on the process itself, calling for more engagement overall with special attention to including marginalized populations (Introduction, Conversation on Health Process, Engagement section).

Examples of public engagement at the local level include a full day workshop on the development of priority setting criteria held by the Grand River Hospital in Kitchener-Waterloo and the engagement by the Winnipeg Regional Health Authority of its Community Health Advisory Councils (CHAC) in development of criteria for priority setting (Gibson, Martin, & Singer, 2005). Regional health authorities in Ontario and Quebec have undertaken public engagement in the form of ad hoc and standing committees, focus groups, key informant interviews, invitations for submission, citizen-led advisory groups, public meetings and hearings, and open houses (Abelson, Forest, et al. 2002).

In addition to these state sponsored consultations, there is plenty of evidence that non-governmental organizations in Canada are taking the idea of meaningful citizen engagement seriously. Two examples include public engagement work of the Sheldon Chumir Foundation for Ethics in Leadership (n.d.) and the emergent Canadian Community for Dialogue and Deliberation (2008) a community of practitioners and researchers in the area of dialogue and deliberation that held its second conference in the fall of 2007.

The literature also bears out the growing commitment to greater public deliberation in health system decision-making. Kenny (2002) suggests, “it is now widely accepted that citizens should be involved in health care decision-making” (p. 210). In their review of the literature, Abelson, Forest, Eyles, Casebeer, & Mackean, (2004) found that "public confidence and trust in representative democracy and traditional political institutions has declined, contributing to a frustrated public, dissatisfied with the status quo yet unable to find meaningful ways to participate in society" (p. 206). They also found that "citizens want to be involved in major public policy decisions (health system decisions in particular) and would feel more confident in government decision-making that 'regularly seeks informed input from average citizens.'" (Ibid. p. 206-207.)

In their own qualitative research with participants who have had experience participating in public engagement exercises in the Canadian health system context, these researchers found that citizen research participants want to participate in policy decision-making, but under the following conditions: that the participation be taken seriously and not be an exercise of window dressing; that the design and process of the exercise be carefully considered to ensure such things as fairness and the right mix of participants; that adequate information is shared and participants are able to have faith that information is not being used to guide discussion in predetermined ways; that citizen input informs the extent of public and expert decisions on an issue; and that exercises of engagement should align with other forms of democratic engagement (Ibid.).[26] The research showed that participants felt that deliberative arrangements could lead to changes in the perspectives of citizens. It also showed that participants felt public trust of decision-makers is vital and needs to be restored. Participants indicated that the key to this restoration is accountability. This was captured in the words of one participant who said "being able to track and just be comfortable that your views were heard and not just heard but actually communicated in reports that come out of these processes in a legitimate way" (Ibid. p.209). The academic interest in deliberative democracy in Canada continues to grow. In 2007 the UBC Centre for Health Services and Policy Research (2007) held a conference entitled *Voices and Choices: Public Engagement in Health Care Policy* where policy-makers, senior civil servants, researchers, and public representatives came together to examine the public's role in health reform.

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[26] It is worth noting that these conditions closely resemble the standards for deliberative dialogue.

That Canadians also see the health system as a symbol of their national identity also indicates that citizen participation is important to Canadians. Under the theme "Canadians value their health system" NFH (1997) writes:

> *Throughout our work, we identified a number of values as central to most people's view of the health system. Our research revealed an interaction of strong vested interests and powerful values (pride, equality, compassion, national identity), which provides the capacity for rigorous debate in the future. At a time when other traditional expressions of Canadian values have been placed under demonstrable stress, health and health care have increased in importance and prominence as a shared and common value. In fact the health system has always engendered strong support among Canadians. In recent years, however, its significance has broadened into symbolic terms as a defining national characteristic.*

Mendelsohn (2002) reinforces this in his report. "It has become commonplace to state that Medicare has become a core component of Canadians' national identity and that it has become symbolically important to Canadians. While this conceptualization is accurate, it risks distracting us from a more important point: Canadians overwhelming prefer the Canadian health care model because they think it is better and fairer" (p.9). Passion and commitment are not passive. These expressions demonstrate that Canadians want to be involved in decisions about health care because at stake for them is their understanding of themselves and of how they want to be seen by others.

The fact that for Canadians health care is a symbol of Canadian identity leads to the importance of public engagement in another way. Healthcare direction setting requires that many challenging, value-laden questions need to be answered. For example, is drug addiction a disease or is it a moral failing? Different conceptual maps of this will lead to different strategies for providing addiction services. In order to determine the goals of harm reduction, we need to know what it means to the community. This is not only about consulting about community values, but requires engaging the public in discussion on substantive issues and helping meaning to emerge.

This broad survey makes the prima facie case that Canadians are committed to being involved in health system decision-making. They do not find it sufficient to have these decisions made for them by these elected representatives. They want meaningful participation in the process. If the parameters are right, not only do Canadians want to participate in decision-making, but also it deeply matters that their views are taken seriously as their very national identity is at stake.

Acting meaningfully to live up to the value of deliberative democracy overlaps with the recommendations described at the end of Chapter Two. It calls for regional leaders to develop a philosophy of justification and public engagement that seeks to nurture the deliberative sphere. It calls for leaders to be transparent about the issues they face, the assumptions they make, and the decisions they take. These are taken up in Cluster A: Understanding and Key commitments and Cluster B: Decision-Making. And it calls for practical strategies for developing a deliberative public sphere around the health system that meets deliberative standards. This is developed in Cluster D: Public Engagement.

### *Accountability, good governance and responsible stewardship of public resources*

A related set of values for Canadians are accountability, good governance and the wise stewardship of public resources. These again are procedural values in that they do not determine what choices to make as much as provide direction about the processes by which decisions are made. In light of structural arrangements, this too entails greater public engagement in healthcare governance. I will first establish that these are values of Canadians. I will then provide an argument linking accountability to public involvement.

The NFH (1997) reports on this value under the theme of "Thriftiness – Responsible Stewardship – Accountability":

> *Accountability is a necessary element of our socially-oriented health system and seen as having two current complementary needs: the need to encourage and educate Canadians toward increased responsibility for health, and the need for increased responsibility in the provision of health care services that meet public needs effectively and efficiently…We found in our work that these values are deeply held and form a solid and stable foundation for public policy.*

On the growing importance of the value of accountability to Canadians, Mendelsohn (2002) writes,

> *The importance of accountability as a general value orientation has also increased in the minds of many, with Canadians expecting greater accountability from governments to citizens. This accountability implies more efficiency from government, a better management of public funds, and fiscal responsibility, particularly after living through the deficits and subsequent cutbacks of the early 1990's.* (p.7)

In terms of legislation, this is indicated by the "public administration" principle of the Canada Health Act:

> This criterion applies to the health insurance plans of the provinces and territories. The health care insurance plans are to be administered and operated on a non-profit basis by a public authority, responsible to the provincial/territorial governments and subject to audits of their accounts and financial transactions. *(Health Canada, 2002,* Principles of the *Canada Health Act*, The Criteria section.)

Fooks and Lewis (2002 p.12-13) found that governance and accountability was one of the nine priorities for health reform that were common to all the reports they studied. They found that specific areas of discussion under this heading included improved federal-provincial relations, more transparent and meaningful performance information and reporting mechanisms, greater clarity around the roles and responsibilities of decision-makers, and new structures supported by the government but directly reporting and accountable to the public.

This is reinforced by professional standards as well. For example, the Canadian Council of Health Services Accreditation (CCHSA) whose accreditation is required for healthcare facilities in Canada to operate calls ethics-based resource allocation as part of its "Leadership and Partnership" standards (CCHSA, 2002). The new CCHSA standards involve significant commitment to organizational ethics.

There is clear evidence that accountability in health system decision-making is important to Canadians. And the desire is that leaders ensure that resources are well utilized. Canadians want their precious health resources to be used efficiently and effectively. I will engage the value of effectiveness below. Here I will consider what the implication of greater accountability is for regionalized health care in Canada.

The central challenge with accountability is that the relationships between key players are ill defined.[27] There are three types of accountability: legal, financial, and moral. Regional boards are legally and financially accountable to ministries of health. The key beneficiary of the organization is the public. A health region is meant to serve the public interest and is therefore morally accountable to the community it seeks to serve. In theory, citizens could have access to three mechanisms for holding regional boards accountable. The first is through elected governors. That is, if communities were able to elect members of their health boards, this might go some ways towards formal accountability relationships. As the government appoints most of the regional health boards in Canada, this is not a possibility. The second vehicle is through community consultation. The problem with this is that most consultation forums put in place by regional authorities are advisory and not empowered. They have been criticized as mere tokenism. So the present understanding of public consultation does not allow the public to hold regional authorities accountable. The third possibility is transparent decision-making by regional leaders. The worry here is that in most cases this transparency represents a one-way communication. Without opportunity for the engagement of reasons behind decisions, this only creates the illusion of accountability.

The reality is that most regional health leaders are accountable to the political masters who appoint them. These political leaders are accountable to the public through elections and the media. In terms of the former, the relationship between system-level decisions taken almost on a daily basis at the regional level and public elections every four years is tenuous at best. In terms of the latter, the kind and quality of the information that passes to the public through the media is limited and biased. There are effectively no public mechanisms by which the public can hold health regions accountable for their decisions. Maddalena (2006) argues that for regional health boards to live up to the value of accountability that is important to Canadians, there will have to be a change in the culture of regional governance. Leaders will have to increasingly share decision-making power. And an infrastructure of civic participation and information sharing will have to

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[27] This argument is largely drawn from Maddalena (2006).

be developed. The extent to which regions are able to live up to the value of accountability, then, will depend on the extent to which public values are taken into account in the system-level decisions made by the organization.

Specific imperatives for leaders that stem from the values of governance and accountability are:

1. Leaders need to account for the decisions they make. The process of decision-making extends to its communication and implementation. Leaders need to articulate decisions, identify the fact and value assumptions the decisions are based on, and justify the balancing that the decisions demonstrate. This rationale needs to be made meaningfully transparent so that the community is able to understand and make sense of this, and then offer comment. Walton et al. suggest that a lack of transparency leads to four serious problems. First, if poor decisions are made, then those affected will unfairly suffer. Second, this will mislead young decision-makers about how decisions should be made, reinforcing poor and unfair practice. Third, it leads to poor understanding of the system and a lack of trust with leaders. And finally, it removes opportunity for debate and diminishes the possibility for reform (Walton, Martin, Peter, Pringle, & Singer, 2006). This is captured in Cluster B: Decision-Making.

2. In order to be able to do the above, leaders need to have rich understanding of the evaluative nature of their own work and to deconstruct the assumptions of the traditions they are working in. They need to be able to deliberate amongst themselves about the fact and value tensions in different situations and engage in dialogue with each other about these. This is captured in Cluster A: Understanding and Key commitments.

3. Accountability and governance calls for leaders to democratize decision-making in the region. If the goal is to meet needs, and needs are evaluative, then the decisions made will need to be informed by the right sets of values. This will require appropriate values based conversation even in areas where great expertise is required. This is reflected in Cluster A: Understanding and Key commitments and Cluster D: Public Engagement.

4. Concerning the overall pattern of the decisions made, these values require decisions that take a long-term view and that ensure consistency and coherence among the services that are provided in regions. Leaders will thus need to ensure that when decisions are made, they are effectively carried out. Accordingly, decisions will need to be accompanied by appropriate follow up, including communication plans to ensure that those that need to know about decisions are made aware of the relevant information and education plans to ensure that those who need training to implement decisions have this. Decisions will have to include evaluation and review plans to ensure that the actual consequences of a decision taken match those anticipated, and to take advantage of any changes in

> facts or values that may arise. And decisions will have to include sustainability plans to ensure the long-term implementation of well-considered and justified decisions. This is captured in Cluster C: Decision Follow-Up.

### ***Health professional integrity and accountability***

Canadians value the professional responsibility of physicians, nurses, allied health workers and others providing their health care and services. This value is not often explicitly addressed. It comes up in this way in Mendelsohn's (2002) report:

> *Canadians continue to have great confidence in health care professionals and 97% believe that they should have an important role in setting policies and ensuring the best possible care, while only about 70% of Canadians believe that governments should have an important role. Although the public recognizes that governments have an important role, Canadians believe that the involvement of health care professionals is essential for success.* (p.19)

That is, Canadians demonstrate this commitment to professionals by wanting them to be involved in decision-making. This speaks to the state of high trust they have for their care providers whom they see are committed to their well-being. Evidence suggests that it is important to Canadians to have professional expertise inform healthcare decisions, and that a) these professionals be held to a high degree of accountability for making decisions in the best interest of patients, and b) that these professionals responsible for providing competent, ethical care. But it is the latter commitment to the provision of safe, competent, ethical care, combined with Canadians' commitment to equity and the wellbeing of all that leads to the most important implications (Pauly, 2004). For there is a lot going on with the ethics related to professionalism and we need to get a much clearer picture of what is at stake with this commitment.

Those working within the health system are moral agents whose integrity – like all human beings – is on the line with every decision they make. Their ability to live with integrity – again like all of us – is impacted by the broader policies of the organizations within which they operate every day. When broader system decisions impact the individual's ability to live out their values, for example, when social workers cannot provide the quality and type of care for patients they feel is appropriate because of resource limitations, there exists a responsibility on the system – the organization – to provide resources to help the affected individual maintain their integrity. These resources range from access to appeals mechanisms for challenging decisions on an ad hoc basis to access to ethics consultation services to help understand the nature of the moral distress that individuals might be experiencing. This organizational responsibility is also justified by the value of accountability. That is, if fairness requires that to hold health care professionals accountable for providing services at a certain standard these individuals must have the resources required to discharge their duties, and if part of the work of healthcare providers is to provide compassionate care, then where the possibility of empathy and compassion are limited by actions taken by the system, the organization has a responsibility to mitigate these effects – including through the types of supports mentioned above.

That Canadians recognize and value the special role of health care workers is reinforced by another source of evidence: professional legislation that governs the conduct of many of these workers. For example, The Health Care Professionals of British Columbia (n.d.) state

> *In British Columbia, virtually all health care professionals are accountable to a regulatory college, board or association. These organizations are responsible, under provincial legislation, for "serving and protecting the public." They do this by ensuring that their members are qualified and follow clearly defined standards of ethics and practice, and that they keep their members up-to-date on new developments in professional practice. The organizations also act when it appears that one of their members is practicing in a manner that is incompetent, unethical or impaired by alcohol, drugs or a mental condition.*
>
> *This public service and protection is provided by the professions themselves. The public is directly involved through government-appointed representatives on the organizations' boards of directors. The organizations also make regular reports to the provincial government.*

This is again a procedural value in that it concerns how individuals (health care providers) are treated as part of the decision-process, and not necessarily what specific content choices need to be made. There are two key areas of implication of this commitment.

1. The values of health care professional integrity and accountability lead to a process-oriented operational cluster about staff engagement. The recommendation

from this cluster is that regional leadership must have in place a staff engagement philosophy and systematic strategies for facilitating staff engagement in the decision process. This philosophy and collection of strategies must recognize the value of staff as experts about the facts that will inform many of the decisions made, including understanding of the context within which decisions are implemented. It must also respect the role of staff as professionals with a responsibility to ensure the ethical care of patients and as moral agents with their own values at stake in the moral enterprise of health care. This is captured in Cluster E: Staff Engagement.

2. By definition, system-level decisions impact groups of people who themselves must make decisions downstream in response to the upstream system decision. Sometimes, indeed often in the setting we are concerned with, system-level decisions make life challenging for those impacted. Accordingly, those working upstream have an important duty to anticipate the difficult positions those working downstream in the system will face as a result of the decision. This recommendation also sees the decision-process as extending beyond the moment of choosing between alternatives. It concerns the way decisions are implemented and follow-up. It requires leaders to a) do what is possible to minimize this impact, and b) seek to ensure support is available to these folks to help them deal with the difficulties they will now face. This is reflected in Cluster C: Decision Follow-Up.

### *Solidarity and compassion: equitable access to services based on need*

One of the main value tensions in healthcare systems is between respecting individual autonomy and the collective good. A strong interpretation of respect for individual autonomy for healthcare structuring and allocation supports the freedom of individuals to buy and sell the goods and services they need according to their own preferences and means. Orientations to collective responsibility favour the state directed redistribution of resources through a system of taxation to provide access to these goods and services based on need, irrespective of individual means. Both of these are substantive values in that they concern actual decisions made rather than the ways in which the decisions are arrived at. The history of this tension is played out in the events leading up to the current health system in Canada. There is very good reason to believe that Canadians are deeply committed to shared responsibility and equitable access for health care.

The NFH (1997) summary describes this key value under the theme of "equality (or fairness)":

> *Equality of access was one of the most important values consistently advocated. Canadians should have equal opportunity to achieve health and well-being and to receive health services according to their needs. The healthcare system allows all of us to share in the costs of health care on the basis of our ability to pay, through income and other taxes. The system is equitable and simple and reinforces an abiding sense of the fairness of equality in opportunity.*

The NFH indicate that:

> *An overwhelming majority of participants stated that Medicare was, and is, an essential part of their national identity. The different approach to health care is one of the main distinctions between Canada and the United States. In a period when the unity of the country is fragile and when people from coast to coast are struggling to find the common values and shared enterprise to keep the country together, it is perhaps both symbolic and disquieting that people perceive Medicare to be threatened as this research suggests.* (Canadian Pride and National Identity section, para. 6)

Mendelsohn (2002) captures both the commitment and the value tension in the following way:

> *Canadians are deeply committed to the idea that their fellow citizens should not be denied good quality health care, but are currently prepared to entertain various proposals that realistically improve the efficiency of the system. Primary health care reform could find a receptive audience. The notion of "purchasing upgrades" may also be consistent with Canadians' values. Few Canadians are comfortable with the idea of the upper-middle-class and the insured driving a health care Mercedes while one-third of the population is consigned to riding around in a 10-year-old Sprint.* (p. 21)

Further evidence is the place of "accessibility" as one of the five principles of the Canada Health Act and documentation providing an overview of the legislation (Health Canada, 2002):

> ***Accessibility:*** *The health insurance plans of the provinces and territories must provide: reasonable access to insured health care services on uniform terms and conditions, unprecluded, unimpeded, either directly or indirectly, by charges (user charges or extra-billing) or other means (age, health status or financial circumstances).* (Principles of the *Canada Health Act*, The Criteria section.)

In their analysis, Fooks and Lewis (2002) found that financing of the health system was a topic that ran through all the reports they considered. In their review they suggest that "Canadian citizens do not appear enamoured of increased private financing as it runs counter to fundamental values of equity and fairness" (p.6).

This evidence indicates Canadians have a clear commitment to distribute healthcare resources based on need and not ability to pay. Although there is broad agreement about this, it is also acknowledged that this tension has a longstanding history (Outellet, 2005) and will likely never go away (Canadian Medical Association Journal, 2006). This is largely because there will always be greater demand than supply of healthcare services, regardless of the quantity of financial resources directed to the system (Hadorn, 2005). This supply-demand relationship requires that healthcare resources be rationed and rationing leads to the creation of waiting lists for services. A number of factors can exacerbate the difficulty that comes with rationing,[28] but regardless, rationing in this way is inevitable in this structure. Waiting lists in turn create pressures to increase efficiency in the system and raise questions about the fairness of not allowing those who might be able to afford to purchase healthcare to do so.

This tension recently flared up with the Supreme Court of Canada decision in the case of *Chaoulli v. Quebec (Attorney General)* (2005). In their majority 4:3 decision, the Court ruled against laws in Quebec that prohibit the sale of private healthcare insurance for medically necessary services. The decision was based on the rationale that

> *the effect of the prohibition on private health insurance is to allow only the very rich, who can afford private health care without the need of insurance, to secure private care in order to avoid any delays in the public system. Given the prohibition, most Quebeckers have no choice but to accept any delays in the public health regime and the consequences this entails.*

The growth of private healthcare clinics in various Canadian provinces is attributed to the decision (CMAJ, 2006). It is also described as capturing an increasing interest in privately available healthcare services.[29] The decision has been roundly

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[28] These range from limits in funding and poor management of resources to high demands for compensation by service providers, lack of adherence to practice guidelines by service providers, and physicians gaming the system to get their patients the care that they might need. See McFarlane (2005).

[29] For example, one Canadian Medical Association vote in favour of legalizing private health insurance in August of 2005, reversing a position held for many years. See Outellet (2005).

criticized for being based on incomplete information (Hadorn, 2005), being inconsistent, and making ill-considered assumptions about the context (Flood, 2005).

While a deeper analysis of this decision and this equally complex issue is beyond the scope of this dissertation, I believe that the decision and context illustrate two points that are relevant to my purpose here. The first is that the value tension between individual freedom and community solidarity is still contested. What the Chaoulli decision has done is rekindle the debate about public health care, and in particular legitimized conversations about possible privatization (CMAJ, 2006). As Hadorn (2005) puts it, Chaoulli has pushed Canadians to think about where to draw the "lines between services that must be provided to Canadians as a matter of justice and those that can be safely relegated to the private market" (p. 271). The second point is that even though the Court's majority decision opens the door for private health insurance, it affirms the value of equitable access to care. That is, the Court's opinion stipulates that in Canadian healthcare legislation need is the determining factor for allocating services. It suggests that the system should provide quality, publicly funded care to Canadians on this basis. Only because the system is not able to meet this demand, the Court deemed private insurance allowable.

What drives this commitment to equitable access is Canadians' commitment to the values of solidarity and compassion. Canadians have a strong orientation towards their common good. This comes out in the ensuring of access to needed services across geographic boundaries, in the importance of public involvement as a means of respecting diversity, in the special attention paid to the needs of the vulnerable, and in the importance of the roles of the federal government and the settings of national standards in the healthcare system.

NFH (1997) captures this value under the themes of "compassion" and "collective responsibility". Compassion is described this way:

> *The common good is of necessity the common concern. Organized effort in the control of health care is due to a desire to protect the strong as well as the weak, and a recognition of our mutual dependency. Social solidarity and concern for the specially vulnerable also exist within the concept of the common good.*

In his report, Mendelsohn (2002) writes that:

> *The role of government remains central in any proposed reform: 81% of Canadians believe that the federal government should be actively involved in the healthcare system. To provide just one example: about 2/3 of Canadians believe that if a national pharmacare programme is introduced, national rather than provincial principles are required. By a margin of 59 to 39%, Canadians believe that the federal government has a key role in sustaining the system and ensuring standards, not merely writing cheques.* (p. 19)

This value is captured in a couple of principles of the *Canada Health Act*: universality and portability. Under universality (Health Canada, 2002) it indicates that

> *One hundred percent of the insured residents of a province or territory must be entitled to the insured health services provided by the plans on uniform terms and conditions. Provinces and territories generally require that residents register with the plans to establish entitlement.* (Principles of the Canada Health Act, The Criteria section.)

Portability requires that:

> *Residents moving from one province or territory to another must continue to be covered for insured health care services by the "home" province during any minimum waiting period, not to exceed three months, imposed by the new province of residence. After the waiting period, the new province or territory of residence assumes health care coverage.* (Ibid.)

I will point to three practical implications of these commitments. The commitments here are substantive. They are about what the right decision in a situation actually is.

1. Leaders should take into consideration both substantive values of equitable access to services based on need and respecting individual choice when making system-level decisions. In their decision process they should articulate how their decisions do and do not live up to both of these values. And where leaders make decisions on behalf of Canadians without meaningful engagement, these decisions should privilege the substantive value of equitable access and meeting the needs of the most vulnerable, ensuring that Canadians aren't privileged because of morally irrelevant criteria. They should choose those alternatives that are most in line with this value. This is captured in Cluster B: Decision-Making.

2. As part of their procedural commitment to nurturing the public sphere, regional leaders should help the communities they serve to think about these values and engage in deliberative dialogue around the value tension. This should include

discussions about how these values are honoured in the context of the Canadian health system, and where they are not honoured. The goals of this dialogue would include helping the community understand what is at stake, deepening the moral discourse around these values in light of the rich context, and determining community value commitments for uptake in actual decision-making. This is captured in Cluster D: Public Engagement.

3. Regional leaders should also facilitate deliberation about the global implications of these values. While it may at first seem tangential to the issue at hand, the global dimension of health resource allocation ethics is actually crucial because of the stakes involved and the logical implications of the commitment to equity. If one believes that the natural lottery is unfair and that as part of respecting human dignity efforts should be taken to equalize opportunities for good health regardless of the socio-economic starting point one is born in to, then it is not at once clear why it should matter where in the world one lives. The worry has to do with the legitimacy of drawing a line of commitment according to national borders.

Canadians' commitment to solidarity could be interpreted in at least two ways. On one hand, it could be seen as the parochial concern for the interests of those living in Canada. On the other hand, it could be seen as a commitment to humanity – the national focus a limitation of the question itself. In other words, Canadians' commitment to each other may simply be a function of a limit set internally by the question itself. The global dimension of health resource allocation ethics is often overlooked.[30] It is important to consider because many local policies have global implications[31] and because it helps us to better understand what a commitment to equity entails. It helps deepen our understanding of whether and to what extent Canadians have an ethical obligation to

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[30] Many would argue that discussions about healthcare in industrialized countries appear absurd and self-absorbed against questions about improving health at the *global* level. While we debate funding MRI machines or transplant programs, most of the world's population struggles with the unnecessary death of children under five from causes that are both easily and cheaply preventable (including dehydration due to diarrhea, malaria, and communicable diseases resulting from lack of access to clean water). We forget that we are discussing how to allocate health resources in a country consistently rated among the world's best in terms of universal access to health care, quality of life, morbidity and mortality rates and life expectancy. This does not diminish the gravity of health resource allocation questions locally. It does suggest that: (1) were we to broaden the scope of our discussions to ask how resources should be allocated to improve health for all people, we would have very different answers to the question of how and what health resources are distributed to Canadians, (2) the context of our health resource allocation discussions is one of incredible privilege.

[31] For example, HR policies that include recruiting caregivers from countries in the developing world have significant impact on the human resource capacity to meet health needs of local populations. See Dwyer (2007).

devote some of their resources to improving the health of those outside their nation's boundaries (in addition to those inside their boundaries who suffer similarly unacceptably low health status). It thus frames the question of resource distribution within a nation like Canada in a new light. This is also captured in Cluster D: Public Engagement.

### *Effectiveness: access to a comprehensive set of high quality services*

There is very good evidence to think having access to effective means for advancing their health is important to Canadians. This also is a substantive commitment about what a good choice would be, as opposed to how to get there. Under the theme of "quality", the NFH (1997) reports that Canadians "want as high a quality of life and health care as possible." Balancing access and quality, they found that:

> *There is a consensus about the importance of equality of access as the defining characteristic of our system. That consensus is premised on the assumption that quality is a given, as people have perceived it to be in the past. However, if quality of service appears to be threatened, the consensus over the importance of equality of access is much less firm... Many were prepared to entertain significant changes in the way the system is designed and administered to preserve quality of care. There did not appear to be a similar willingness to accept significant reductions in the quality of care to preserve access.*
>
> *Most participants demanded a very high standard of quality of care. Almost all seemed to accept that, in the world of endless technological advances and spiraling health care costs, not everything would be possible in our system. For example, most had no problem with the use of a less expensive heart drug in exchange for a minor increase in risk. But, on the other hand, participants volunteered concerns about a brain drain of doctors as evidence of their worries about the ability to maintain quality in our system with decreasing or insufficiently increasing dollars.* (The Twin Pillars of Access and Quality section.)

Mendelsohn (2002) reports the following about the importance of quality to Canadians:

> *When Canadians are asked, they consistently say that we should not cut spending on health care. In 2001, 78% of Canadians said we were not spending enough on health care, while only 4% said we were spending too much. Canadians consistently say that our system does not cover too many services and are willing to pay to ensure quality...*

> *Concerns about the quality of care, understood as timely access to the best quality care, have increased in recent years... "Quality" and "equal access for all" are now judged to be of equal importance. Yet in 1998, 64% of Canadians agreed that "we need to maintain equality of access, even if it means that we cannot have the highest quality care." And as discussed below, access remains particularly important for the more economically vulnerable, a difference that cannot be overlooked in any proposed reform.*
>
> *...The two clear messages emerging from these polls are that Canadians have become increasingly concerned about the quality of care provided by the healthcare system, and that quality and access can be understood as the two key principles of the healthcare system to which most Canadians are deeply attached.* (p. vii)

Fooks and Lewis (2002) found that developing plans for pharmaceuticals and home care were important themes in the health reform reports they studied. This speaks again to the importance of access to a comprehensive set of healthcare resources to Canadians. Additional themes include primary care reform and quality, performance measurement, and information systems. The fact that these themes emerged as the focus of health reform reviews point again to the emphasis Canadians put on receiving effective, quality care.

A principle in the Canada Health Act is "comprehensiveness": "The health insurance plans of the provinces and territories must insure all insured health services (hospital, physician, surgical-dental) and, where permitted, services rendered by other health care practitioners." (Health Canada, 2002, Comprehensiveness section.) Taken together, this evidence clearly suggests that it is not simply access to a comprehensive set of care and services that Canadians value, but access to care and services of high quality.

Implicit in this is an important assumption that identifies a central tension in Canadians' approach to health care. The NFH quote above points to equitable opportunity to achieve health, due to its strategic importance in the achievement of the life goals of individuals. But the Canada Health Act principle of comprehensiveness privileges a certain type health determinant: access to hospital and physician services. The assumption is that access to the types of health care offered by physicians and in these facilities are an important determinant of health and well-being. That is, another rendering of the value of access to a comprehensive set of high quality services is the value of effectiveness. Canadians seem to want to know that the services they have access to will be effective in meeting their health needs.

Two concerns need to be identified here. First, public engagement is required to understand what needs should be met. Effectiveness, efficiency, and even quality are instrumental values that need to be defined by broader understandings of the goals of the endeavour in question – here the healthcare system. If the goal is to meet needs, we need to understand what those needs are. If the goal is to meet needs equitably with special attention to the vulnerable, then we need to have an equitable system for understanding what the needs of people are, with special attention to the needs of the most vulnerable. Health is an evaluative notion that is informed by individuals' and communities' values and beliefs – what a good and meaningful life looks like. Health care, to be effective, must be based upon an accurate understanding of what a good and meaningful life looks like for the recipients of care.

Second, the assumption about access to health care impacting health is questionable. There has been historical doubt over the effectiveness of health care in determining health status (Evans and Stoddart, 1990). New evidence has brought us to the point where it is generally accepted that health care has a relatively small contribution to make to the overall health of populations and that wider determinants well beyond the scope of health care, such as income and social status, education, employment, social support, personal health practices and choices and the physical and natural environment, have a greater impact on health (Evans, Barer & Marmor, 1994). In fact, studies indicate that where we stand in the socio-economic hierarchy of society – regardless of how well of or poor we are – is proportionally related to how long we will live and the level of health we will enjoy while we are alive. For example, it has been observed that the relative positions we occupy in the classes within our society is directly related to our chances of getting and succumbing to different diseases. A person who is on a lower rung in the social ladder is not only more likely to smoke than someone above who smokes, but is also more likely to get sick and die of a smoking-related illness than someone in a higher socioeconomic class who also smokes. This gradient is true even well above what are regarded as standardly accepted (Western) levels of poverty (Ibid.).

Yet, despite acceptance that the determinants of population health lay outside medicine, our health policies have remained medicine-centred (Ibid.).

There are three practical implications of these commitments and their implications.

1. There is a strong prima facie case to be made that Canadians value access to a comprehensive set of high quality healthcare services. Decision leaders should facilitate meaningful deliberation in the community about these values. In particular, the above discussion calls for deliberation on the tension between high quality services and universal access. Because these are instrumental values, this must mean that Canadians value improvement in their health status. Leaders will have to help the community understand the significance of the literature on the determinants of health and to help Canadians to clarify their value commitments in light of this. This is captured in Cluster D: Public Engagement.

2. Until a public sphere that lives up to deliberative ideals is created, decision leaders will have to guide their decisions keeping in mind and responding to the values of quality, comprehensiveness and effectiveness. They should choose those options that best secure access to effective, high quality, comprehensive services. Another area of focus in health reform reports that Fooks and Lewis (2002) reviewed had to do with population health: "While the language varied slightly across jurisdictions, the policy goal was the same – to improve the health status of citizens through mechanisms other than the traditional health care system" (p.2). However, they suggest that even though this appears to be a keen area of interest, little in the way of a meaningful population health approach has actually been taken. Leaders will have to keep the broader value of improving health status top of mind in making their system-level decisions. This in turn will mean paying attention to the forces that favour medicine over public health and the social determinants of health (Daniels and Sabin, 2002). In other words, leaders should choose alternatives that really will be effective in improving health status, being mindful of and resisting pressure from forces that privilege less effective, though historically privileged modalities of care. This is reflected in Cluster B: Decision-Making.

3. As the notion of health is itself evaluative, in order to meet health needs regions will have to support public engagement initiatives that help members of the community reflect on and articulate what their vision of healthy and meaningful life looks like and what the health system can do to facilitate advancement of health status. This is also captured in Cluster D: Public Engagement.

## Summary and Next Steps

I have suggested that the sources I have turned to are accurate indicators of the values of Canadians. If my interpretation and analysis of these sources is reasonable, then a number of recommendations arise for leaders as part of the imperative to live up to these values. The value of participatory democracy reinforces the recommendations arrived at in Chapter Two. The remaining values named in this section lead to recommendations concerning the self-understanding that leaders and leadership teams operate with, elements of the decision process the team adopts, engagement of the community the region serves, and engagement of the physicians and staff working in the region. Most of the recommendations concern the process by which decisions are made, while a few are about what choices should be considered ethically superior.

The first collection is all about process and concerns the self-understanding of leadership. It is important for leaders to:

- Have a rich understanding of the evaluative nature of their own work,
- Deconstruct the belief and value assumptions of the traditions they are working in,
- Deliberate amongst themselves about the belief and value tensions in different situations.

Also process-focused, the second set of recommendations is about the way leadership goes about making decisions. They should ensure their process:

- Democratizes decision-making, creating appropriate space for discussion of values for evaluative dimensions of all decisions, in even the most complex situations
- Takes a long-term approach with a view to ensuring consistency and coherence among the services that are provided in regions
- Accompanies decisions with appropriate communication, education, evaluation, review and sustainability plans
- Anticipates the difficult positions those working downstream in the system will face as a result of decisions, try to minimize this impact, and make appropriate support available.

Again concerning process, and resonating with the findings in Chapter Two, reinforced by Immanent Value 1, leaders and leadership teams are called to facilitate meaningful public engagement:

- Decisions should be transparent to the public. Specifically, what decisions are made, the fact and value assumptions the decisions are based on, how these are balanced, what trade-offs are required, and the justification for this balancing should be shared with the public in a way they can access, understand, and offer response to.
- The community should be helped to understand what is at stake in regional decision making with particular efforts aimed at the uptake of the ideas behind the broader determinants of health should be made.
- Deliberative discussion about the significance of the values of equitable access to services based on need, the global implications of this, respecting individual choice, the tension between high quality services and universal access, effectiveness in light of broader determinants of health their vision of healthy and meaningful life, and what the health system can do to facilitate advancement of health status.
- The goals of engagement should include deepening the moral discourse around these values in light of the rich context and determining community value commitments for uptake in actual decision-making.
- Leadership should also develop staff engagement philosophy and strategies along similar lines. There are also two substantive recommendations that come from this analysis. In the absence of a deliberative sphere, leaders should:
  - Explicitly consider the values (some of which are in tension) of equity, respecting individual choice, quality, comprehensiveness and effectiveness, and the broader value of improving health status.
  - Ensure equitable access to services and attention to the forces that favour medicine over public health and the social determinants of health.

In suggesting that these values could stand in for deliberative outcomes while a deliberative infrastructure is developed, one might wonder why this process wouldn't fall prey to the pitfalls I have ascribed to principlism—that it's not at all obvious how the values can be non-arbitrarily balanced. In response, I would first say it is important to acknowledge that using these principles does not yield legitimate decisions. On the account I have offered, a rich deliberative sphere is required for this. Until a rich enough public sphere develops, the legitimacy of decisions will be in question. But while this public sphere emerges, there are it seems several alternatives. We could turn to the views of elites and experts in positions of authority in the system. We could turn to Canadian moral theorists. Or we could try to make a substituted judgment for Canadians, approximating their perspective from available evidence of their views. I suggest that the latter is closest to the democratic ideals I have defended. The values that emerge as immanent in the Canadian health system from the sources I have considered are more justified to stand-in than the views of elites and experts who occupy positions of authority within Canada's regionalized health system or the philosophers in the ivory towers of Canadian universities. To be clear, I am not suggesting that leaders choose between two exclusive options: either engage the public or attempt to substitute the judgment of the public. Rather, I am advocating for maximizing the consultative mechanisms that are available, instituting new ones as aggressively as possible, and attending to immanent values where necessary.

I turn in the next chapter to developing more operational recommendations to help decision-leaders to guide decisions and the processes by which they are made to be more consistent with these values and the theoretically derived approach of deliberative democracy defended in Chapter Two.

# CHAPTER FOUR: FIVE CLUSTERS OF OPERATIONAL RECOMMENDATIONS

## Introduction

To this point I have offered normative direction about what would make the decisions of regional health leaders justified. In Chapter One I argued that system-levels decisions in health care are intrinsically evaluative. I suggested that in the context of pluralist societies such as Canada, approaches that offer a theoretical defense of substantive norms would not provide sufficient grounding for decisions to be justified to people from diverse value perspectives. Instead a process-driven approach is necessary.

In Chapter Two I defended the theory of deliberative democracy, as the most likely to offer the kind of direction required. I provided a detailed account of this perspective. I suggested that legitimacy for decisions in a pluralistic context comes from meeting a strong notion of the value of publicity where decisions are made in the context of a rich public sphere. The journey to legitimate decision-making thus requires health regions to both develop an infrastructure of public engagement that meets the deliberative ideals of citizen participation and formally tie their decision-making to the outputs of this complex of public engagement mechanisms.

Then in Chapter Three I provided an account of values embedded within the Canadian regionalized healthcare system. I argued that these values should be taken into account in the decision-processes of regional leaders. The procedural values of participatory democracy and accountability resonate with the directions from deliberative democracy and underscore the recommendations from Chapter Two. The value of respect for healthcare professionals needs to be reflected in the way decisions are made (by giving care providers voice) and followed-up (by supporting those who will experience moral distress as a result of upstream decisions). The substantive values of equitable access and effective, quality, comprehensive services need to be reflected in deliberations about decisions, particularly in the absence of a rich public sphere.

In this chapter my goal is to consolidate the normative directions provided so far into an integrated set of operational recommendations for leaders. I offer five clusters of directions that ensue from the argument for deliberatively democratically guided health care in Canada (developed in Chapter Two) and from the values I suggest are immanent in Canada's health system (described in Chapter Three). The idea is if leaders act on this advice, the decisions made in the health system will be legitimate.

The recommendations are not the conclusions of a formal logical argument, but capture the spirit of the normative directions indicated so far. The recommendations are meant to be easier to understand and to operationalize for the busy health care leader than the broader argumentation so far. They will also indicate the content that decision support instruments for regional health leaders should include, instruments such as the system-level health care decision-making workbook that is recommended in Chapter Six and an example of which is provided in the Appendix B.

The five clusters that my recommendations fall into are:

A. understanding and key commitments.
B. decision-making.
C. decision follow-up.
D. public engagement.
E. staff engagement.

More specifically, for health system leaders to make decisions that are legitimate, they will need to:

1. Appreciate the evaluative nature of decision-making and increase their ability to speak together about values and beliefs. (A1)
2. Commit to a rich understanding of publicity and to the development of a public sphere around the healthcare system. (A2)
3. Understand the idea of democratic complexity and commit to democratizing the decision-making that happens at the system-level in the organization. (A3)
4. Review and revise the internal decision dynamics at the region. (B1)

5. Directly consider substantive values immanent in the Canadian context in their decision analysis. (B2)
6. Make transparent the decisions made, the value-trade-offs these involve, and the justification for this balancing. (B3)
7. Ensure decisions are appropriately followed up and include:
    - Education plans to ensure that those who need training to implement decisions have this. (C1)
    - Communication plans to ensure that those that need to know about decisions are made aware of the relevant information. (C2)
    - Sustainability plans to ensure the long-term implementation of well-considered and justified decisions. (C3)
    - Downstream support plans to assist those who will be put in morally compromising situations as a result of the upstream decisions. (C4)
    - Evaluation and review plans to ensure that the actual consequences of a decision taken match those anticipated, and to take advantage of any changes in facts or values that may arise. (C5)
8. Develop a philosophy of public engagement (D1), including:
    - The identification and refashioning of existing forums where these might exist to make them more deliberative. (D2)
    - The creation of new deliberative processes within the public sphere. (D3)
    - Exploring areas where affected parties are not connected enough to have access to decision processes and actively seeking to overcome this. (D4)
    - Developing an interim public engagement approach for use until the broader public sphere is effective. (D5)
9. Develop a staff engagement philosophy and strategy. (E1 & E2)

These categories are artificially bounded in the sense that specific recommendations may actually fit into more than one category. In particular, clusters A, B, and C could all be collected under a single "supercluster" as they all concern some aspect of the decision process leaders follow. As mentioned in Chapter Two, parts of Clusters A, B, and D could also be collected under a broader cluster of public engagement. My sense is that the specific recommendations in this particular configuration are easier to understand. I hope this way of organizing the recommendations is useful and that this makes it more likely that they will be acted on.

A reader familiar with the regional healthcare context might find it unrealistic that a leadership team would be able to meet this comprehensive list of recommendations. As Goodin (2001) reminds "it is pragmatically pointless to pursue outcomes that are impossible" (p.202). Having worked with pragmatically-minded leaders for the last decade, I am aware of the need for "doability." I will respond to this concern after offering a more detailed description of each of these clusters of operational recommendations. It is to this description I now turn.

### Cluster A: Understanding and Key commitments

This cluster concerns the thinking and orientation of leaders and leadership teams. It describes the approach that leadership teams should have and it identifies certain precursors to action. There are three specific recommendations in this cluster. Regional leaders should:

1. Appreciate the evaluative nature of decision-making and increase their ability to speak together about values and beliefs.
2. Commit to a nuanced understanding of publicity and to the development of a public sphere around the healthcare system.
3. Understand the idea of democratic complexity and commit to democratizing the decision-making that happens at the system-level in the organization.

#### *A1: Understand the values dimension and engage in values-talk*

In Chapter Two I suggested that for all system-level decisions, leaders should articulate not only the decisions taken, but also describe the reasons upon which decisions are based, the value trade-offs that each decision requires, how these trade-offs are justified, and the processes used to arrive at the decision. To make this happen will require the ability to understand, appreciate and articulate the evaluative nature of this work. It will require leaders to have a shared language for talking about these value dimensions. So the first direction has to do with regional leadership's own understanding of the evaluative nature of the decisions it makes. This is instrumentally important as it speaks to capacities that are necessary in order to live up to the value of publicity, and some of the other procedural values that are immanent in the Canadian healthcare system. Specifically, leadership should:

- Recognize that the decisions they are making and the way that these are made are based on values and beliefs.
- Recognize their own personal values and beliefs and how these impact their professional work.
- Be able to identify the specific values and beliefs that system-level decisions are based on.
- Develop a shared language for critically and systematically engaging the values and beliefs that are at stake in issues.

Again, all decisions have an evaluative component, so the task is not to understand *which* of the types of decisions made are evaluative, but what the value dimension of these decisions is.

Naming this as a value is important because in my experience, Canadian regional decision-making bodies in the health setting operate without much understanding of the democratic context within which they operate or a clear vision of their role within a democratic society. Many leaders do not recognize or question the real values, substantive or procedural, which both do and that ought to govern their decision-making question, or the moral authority they have to make decisions. (After all, they have likely been hired to lead.)

### *A2: Commit to the value of publicity and building a public sphere*

This set of operational recommendations for regional leaders calls for a commitment to a strong notion of publicity and to nurturing a sphere of public engagement around the health system. The recommendations about the demands of publicity and the call of a rich public sphere are daunting and represent huge challenges for leaders, especially in light of the modern context of the healthcare system. This is in part why I have broken the recommendations related to this into three subsections. This step is a precursor to the recommendations for transparency in decision-making (in Cluster B) and actual nurturing of the public sphere (Cluster D). The path to this commitment can be divided into two steps. The first is engaging the normative and descriptive assumptions on which my defense of deliberative democratic theory applied to Canadian health system is grounded. Leaders should intentionally work to develop a perspective on the social facts of pluralism, the capacity of individual citizens, how identity is formed, the self- and community-interests of citizens, and what can be achieved through meaningful dialogue. And they should explore what they understand is required in demonstrating meaningful respect for citizens, what democracy entails, what model of citizenship they advocate, and what their orientation to the values of equality, inclusiveness, and trust is. They should consider the different understandings of democratic legitimacy and the standards these various perspectives place on policy decisions.

The second step is actually making a commitment to publicity and the public sphere. If they are convinced by the arguments I have offered in Chapter Two, then leaders will have to accept that what makes decisions legitimate is the extent to which these decisions are arrived at through ideal deliberative processes in the public sphere. Grounded in a response to pluralism, they will understand legitimacy as derived from accountability. They will seek to build trust with the public and see the demonstration of accountability and living up to the norms of publicity as the route of this trust building. All this starts with a commitment to the value of publicity. Specifically, leaders in the health system will need to commit to make known the values and beliefs that underpin their decisions in a meaningful way (B1). Moreover, they will have to make explicit and facilitate a rich understanding in the community about the evaluative nature of the decisions that leaders are making in the health system and the particular values and meanings at stake in particular issues (D1).[32] And they will need to commit to building a rich public sphere through which meaningful uptake can happen. (This is taken up in more detail in Cluster D.)

One reason for this step is that policy decisions must be grounded within a socio-political context. In light of the complexity of the health system, with so many different

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[32] As we saw, this in turn will require the ability to recognize that their decisions are based on process and content values and they will need to understand what various process and content values are and what these commitments mean. It will require the development of a shared language for talking about these value dimensions. And leaders will also need to be able to recognize own personal value commitments (A1).

actors, layers of decision-making, and a complicated professional hierarchical structure, meaningful engagement of a policy-making process that takes democratic legitimacy seriously will require the deliberate, intentional action of organizational leaders.

### *A3: Commit to the democratization of decision-making*

Part of the commitment to publicity is the obligation to achieving democratic complexity in the system. Leaders should determine the extent to which true complexity is necessary and where there is need for engagement with the public sphere.

The procedural values of participatory democracy, accountability, and governance all call for leaders to democratize decision-making in the region. If the goal is to meet needs, and needs are evaluative, public engagement on needs must happen. If decisions are based on values, and values are to be settled by a deliberative public in a democratic society, then public engagement must happen. In both cases this is required not instead of but together with appropriate technical expertise. In a sophisticated understanding of the need for legitimate mediation of the evaluative dimensions of decisions within their complex system, leaders will recognize that experts and elites continue to play a crucially important role in the decision making process in the scientifically and politically complex context of health care. Decisions made at the system-level have meaningful public input alongside and on an ongoing basis. Every system-level decision need not be made directly by a specific deliberative public forum. These decision processes can justified if they themselves are the objects of appropriately structured engagement with the public.

## Cluster B: Decision-Making

This cluster concerns the actual decision-making processes within the system and includes three areas of recommendation. Leaders should:

1. Review and revise the internal decision dynamics within regional leadership teams.
2. Directly consider substantive values immanent in the Canadian context in their decision analysis.

3. Make transparent the decisions made, the value-trade-offs these involve, and the justification for this balancing.

### *B1: Internal decision dynamics*

This recommendation concerns the behaviour of leaders and leadership teams as they make decisions. Honouring pluralism as a value and recognizing pluralism and inequality as facts about society, leaders will have to strive to manifest ideal deliberative procedures in their own decision processes. In the decisions they actually make, leaders should seek to demonstrate the values of reflexivity, equality, pluralism, inclusiveness, and recursiveness. They should ensure that decisions are reason-driven, and not based on power dynamics, bargaining, horse-trading, and the like. The processes should enable leader-deliberators to share their reasons for action, hear the reasons of others, and engage each other about these reasons with a view to developing a shared approach to the issue whereby all perspectives are maximally honoured and participants are able to live with decisions made. This will be especially important until a public sphere is developed.

In other words, the processes should allow the decision-makers to reflect on their own perspectives and understand their value commitments, and engage each other such that respective value commitments may change. These processes should formally consider different value perspectives in their deliberations, and meaningfully engage these. Wherever possible, they should allow different perspectives to be presented by those who hold them. A useful guide for this might be an altered form of Young's test of inclusion: if deliberations about a decision concern a segment of the population that is not represented by the deliberators, whose perspectives deliberators cannot meaningfully relate to, and who have little power to hold decision-makers accountable for their decisions, then this group is effectively excluded from the decision process and leaders should find a way to create an avenue for their perspective to be directly heard and engaged. And the process should enable leaders to openly question the very framework of decision-making that is used to raise again past decisions that have already been made for retrospective analysis.

As teams explicitly address how they will operate and treat each other, it will be helpful to answer specific questions about their mandate, the equality of members' views, their approach to dealing with difference, what counts as evidence, and how disagreements are to be resolved. Consider the example of a regional pandemic planning committee struck to develop the organization's pandemic preparedness plan. When assembled, the group will have to come to terms with a number of questions about how they relate to one another.

As the group engages its work, it will have to be clear on its authority to make decisions. In other words, as different issues are tackled, what will be the status of any decisions made? Will they be binding? An important question the group will have to determine is who will get a voice at the table. That is, often having a space at a decision table is not enough to have one's perspective meaningfully heard. This is especially true in the hierarchical culture of health care where decision authority, rather than richness and importance of perspective, is the determinant of who is heard.

Any issue that is worth struggling with often has at least two legitimate perspectives. What will the group's attitude be towards different, and sometimes difficult to hear and unpopular perspectives on issues? Will this difference be actively sought out and meaningfully engaged? Or will it be silenced in effort to get decisions made and not rock the boat? When an issue is being dealt with, how will a conclusion be reached? Will the most powerful member of the group take the conversation under advisement and make the decision himself? Will the group vote on the issue? Will the group struggle until a consensus is reached? Will the perspective of the person with the most stamina or loudest voice be the last to be heard and carry the day? As discussed in Chapter One, beliefs are one of the two main factors in decision-making and ethically justified decisions rest on the best available facts at the time. The challenge is that we have different standards of evidence for what counts as a fact. Is it enough that we have anecdotal evidence from what we consider to be reliable sources? Do we require a degree of scientific rigour? What is this standard?

Key values that should guide these decisions include trust, honesty, humility, sincerity, meaningfully treating others with respect, equality, basing decisions on reason and not power, coercion, or manipulation. This cluster of recommendations will be a precursor to the clusters of public and staff engagement. In other words, until regional leaders are able to take seriously and make gains towards developing and implementing meaningful approaches to engagement, it will be important for them to model patterns of ideal communication. However, once these strategies are in place, the significance of this becomes less important as the values of equity, efficiency, solidarity, democratic legitimacy, and professional accountability will be served better by justified and well functioning engagement strategies.

Again, in order to be able to do the above, leaders need to have rich understanding of the evaluative nature of their own work and to deconstruct the assumptions of the traditions they are working in. They need to be able to deliberate amongst themselves about the fact and value tensions in different situations.

### *B2: Direct consideration of immanent values*

Leaders should take into consideration both the substantive values of equitable access to services based on need and respecting individual choice when making system-level decisions. They should articulate how their decisions do and do not live up to both of these values. And where leaders make decisions on behalf of Canadians without meaningful engagement, these decisions should privilege the value of equitable access and meeting the needs of the most vulnerable, ensuring that Canadians aren't privileged because of morally irrelevant criteria.

Until a public sphere that lives up to deliberative ideals is created, decision leaders will have to guide their decisions keeping in mind and responding to the values of quality, comprehensiveness and effectiveness. Another area of focus in health reform reports that Fooks and Lewis (2002) reviewed had to do with population health: "While the language varied slightly across jurisdictions, the policy goal was the same – to improve the health status of citizens through mechanisms other than the traditional health care system" (p.2). However, they suggest that even though this appears to be a keen area of interest, little in the way of a meaningful population health approach has actually been taken. Leaders will have to keep the broader value of improving health status top of mind in making their system-level decisions. This in turn will mean paying attention to the forces that favour medicine over public health and the social determinants of health (Daniels & Sabin, 2002).

### *B3: Transparency*

Leaders need to account for the decisions they make. They need articulate these, identify the fact and value assumptions the decisions are based on, and justify the balancing that the decisions demonstrate. The rationale behind a decision needs to be made meaningfully transparent so that the community is able to understand and make sense of this, and then offer comment. The reasons provided should include the explicit responses of decision-makers to the various different perspectives considered and engaged.

For the goal of democratizing the complexity in the system to be achieved, leadership will have to understand and make explicit to what extent the decisions they encounter are evaluative. They will have to see for themselves the types of value trade-offs that these decisions require. And they will have to make the evaluative dimensions of these decisions, including the value trade-offs at stake, public. That is, they will have to help the community, in specific terms, to see and understand the evaluative nature of system-level decision-making in health care. So leaders will have to make the evaluative nature of their decisions and the value-trade offs entailed meaningfully transparent.

There are two reasons for this set of recommendations. First, in response to the value of accountability, this degree of transparency will be necessary to demonstrate the evaluative challenge of ensuring the provision of effective services efficiently and to show how they have actually met this goal. Demonstrating success at achieving a goal requires making clear and justifying the goal being aspired to in the first place. In other words, to demonstrate the success or failure of leadership in providing services, the services themselves will have to be justified.

The second reason for having to make assumptions about values and beliefs clear is that part of a meaningful public engagement strategy will be developing an agenda for discussion. Key to the setting of an agenda will be leadership identifying and making transparent the kinds of trade-offs they have to make, and laying bare the processes, decisions, and assumptions that lead to the articulating of these trade-offs in the question at hand.

### Cluster C: Decision Follow-Up

The values of public participation, accountability, and professional integrity require decisions that take a long-term view and that ensure consistency and coherence among the services that are provided in regions. Leaders will thus need to ensure that when decisions are made, they are effectively carried out. Accordingly, there are five recommendations in this cluster: Decisions should be followed up and include appropriate:

1. Education plans to ensure that those who need training to implement decisions have this.
2. Communication plans to ensure that those that need to know about decisions are made aware of the relevant information.
3. Sustainability plans to ensure the long-term implementation of well-considered and justified decisions.
4. Downstream support plans to assist those who will be put in morally compromising situations as a result of the upstream decisions.
5. Evaluation and review plans to ensure that the actual consequences of a decision taken match those anticipated, and to take advantage of any changes in facts or values that may arise.

All system-level decisions should be expected to include these and considered a crucial part of the region's policy on policies. For example, a decision at the regional level to limit access to ventilated beds only to certain types of patients will leave the physicians and staff working for the region who must decide which of their patients best fit that criteria and then what to do with those that do not – when all of them might likely benefit from the resource. In this example, the clearer the rationale offered at the regional level about why the decision is made and the better processes in place for appealing the policy, the more likely it will be that those affected will be able to live with it. In addition, the regional decision-makers might provide training in bedside resource allocation decision-making to those impacted to help support those impacted.

### *C1: Education strategy*

In many cases, system-level decisions will require follow-up by staff. For example, decisions about what kinds of masks will be provided to staff during an influenza pandemic, where alternate centres of care will be provided for influenza patients, and what processes will have to be followed in terms of human resource issues will all have very important implications for staff, patients, and families alike. These system-level decisions should be accompanied by appropriate education strategies that reflect carefully on which individuals will need access to what information. If decisions involve change management, the strategies will have to be based on an understanding of the best change management practices.

### *C2: Communication, review and revision strategy*

Consistent with the support for a deliberative public sphere, decisions will have to include communications strategies for the decisions that have been made by leaders and the rationale for these decisions. The rationale will need to point to what values were found compelling enough to guide decisions made, what values were recognized as important but that did not carry the day, and how this balancing was justified. Communication will also have to include how one might have one's voice heard about the issue and how such ongoing input is to be handled – how it will inform future decision-making processes.

### *C3: Sustainability strategy*

Many system-level decisions have broad implications, especially if they lead to changes or involve initiatives that outlive the decision-process by which the decision is made. System-level decisions need also consider both how the decision made and the deliberative sphere around the decision will be sustained. For example, many planning groups for the influenza pandemic have time-limited mandates. But a flu pandemic may not arrive for several years. In the decision-making of such planning groups, a clear plan for how the thinking to guide decisions around the pandemic should happen after the group's disbandment and how the decisions taken by the group might need to be revisited will need to be in place.

### *C4: Downstream support strategy*

By definition, system-level decisions impact groups of people who themselves must make decisions downstream in response to the upstream system decision. Sometimes, indeed often in the setting we are concerned with, system-level decisions make life challenging for those impacted. For example, decreasing the budget of a program or not increasing it to match need creates challenges of micro resource allocation for program leaders. Without a clear understanding of how to make the evaluative judgments about which individuals should and should not receive services, this can create enormous moral difficulty for the leaders in charge. These will need effective tools to be able to make the best decisions possible in these difficult circumstances. They may also require emotional and professional support if the choices are particularly traumatic. Accordingly, those working upstream have an important duty to anticipate the difficult positions those working downstream in the system will face as a result of the decision and a) do what is possible to minimize this impact, and b) seek to ensure support is available to these folks to help them deal with the difficulties they will now face.

### *C5: Decision process evaluation strategy*

Included in any decision process will have to be a reflexive strategy for examining how well the process lived up to the values it is based on. Questions such as the following will provide leaders with a strong sense of whether decisions actually do meet the standards of justification set out here:

- Were the perspectives of differing voices formally considered in decision-making processes?
- Did justifications for system-level decisions provide explicit responses to different perspectives?

- Were persisting fundamental disagreements handled with meaningful mutual respect?
- Does the approach demonstrate openness to the possibility of achieving solutions that can respect a broader range of values?

These five recommendations and decision criteria in this cluster are theoretically consistent with those from the other clusters of operational considerations.

### Cluster D: Public Sphere

When a rich, decentered public sphere is developed and meaningful transparency is achieved, system-level decisions will be justified to the extent that they are not resisted in this public sphere. So together with meaningful transparency and democratic complexity the region, through its leadership, should actively support deliberative practices in the community and seek to build a political public sphere around the health system. This effort will need to go beyond the veneer public participation. Given the absence of the public sphere as concerns the healthcare system, this leads to the following five recommendations:

1. The development of a philosophy of public engagement.
2. The identification and refashioning of existing forums where these might exist to make them more deliberative.
3. The creation of new deliberative processes within the public sphere.
4. Exploring areas where affected parties are not connected enough to have access to decision processes and actively seeking to overcome this.
5. Developing an interim public engagement approach for use until the broader public sphere is effective.

Healthcare leaders should see the public sphere as taking many forms beyond the understanding of the conventional town hall meeting. This notion should be expanded to include broad structures of public engagement, formal, public decision-making authorities, work in associations and existing groupings in civil society, and the kinds of minipublics that Fung points to. They should also recognize that citizens face inequalities with respect to accessing the public sphere, some of which are deeply structural taking the form of biases in certain discourse and forms of communication. They should seek to understand how and where political domination occurs, and they should seek to find ways to overcome this domination to create genuine equality and inclusiveness in the public sphere they support.

In general, the recommendation and decision criteria provided by the public engagement cluster of operational considerations is consistent with the other considerations of making ethics explicit, demonstrating ideal communication, staff engagement, and downstream planning. There may be tensions with the values of the public that become identified through engagement with minipublics and the values of leaders and leadership team and organizational staff. However, the overall regional engagement philosophy and strategy should include a normative commitment and plan for dealing with these tensions when they arise.

### *D1: Philosophy of public engagement*

The argument in Chapters One and Two leads to the conclusion that the legitimacy of decisions made at the system-level in health care depends on the public deliberation that informs them. This is reinforced by commitments to participatory democracy and accountability found inherent in the Canadian health system. Public engagement is also required to live up to the value of effectiveness, also immanent in the system. That is, in addition to the need for a deliberative procedural approach to deal with the value pluralism of society and the identification of democratic legitimacy as a value of Canadians, there are four reasons for meaningful public engagement.

First, the raison d'etre of the system – advancing health and well-being – is not objective but evaluative. Thus, to advance the health of members of the community, the region must have some understanding of what members believe the ends of human life to be, which in turn requires their political participation. If the objective of the system depends on an interpretation of health and wellbeing, we need to understand what health and wellbeing look like for members of the community and how they see this being achieved. Leaders will need to engage the community help understand its own sense of health and what meeting health needs will look like. Otherwise it is not possible to meet this need efficiently and effectively.

Second, in a context where people have a spectrum of values, beliefs and understandings of what a meaningful life involves, possess a wide range of capacities to attain well-being, and occupy different places in a fairly broad hierarchy of socio-economic status, there will be tremendous variance in the health needs of different people. In diverse contexts, the problems of ethnocentrism, androcentrism, ageism, ableism, "medicalism" and other forms of discrimination based upon a misunderstanding of the moral authority of some viewpoints can be exacerbated. Equity involves recognizing differences in the needs of people and meeting the respective needs of different individuals and groups in a situation sensitive manner. To live up to the value of equitable access, leaders will have to find ways of hearing the voices of the vulnerable in the development of their responses to meeting needs.

Third, meaningful public engagement and participation in the decision process is itself a means of empowering people over their own destiny. It is a way of demonstrating meaningful political self-government, which can by itself have salutary health effects. Leaders can use this vehicle as a means of actually generating health gains (Buchanan, 2000).

Fourth, healthcare is where identity is forged. Their identity is important to Canadians and they see the healthcare system as a representation of this. But identity is not static. If growth and self-understanding comes from resolving values in tension, then leaders have an obligation to provide support on this journey. The formal recommendation here is that leaders need to develop an overall philosophical approach to public engagement. It is important to be clear that the recommendation is not for regional bodies to simply go out and initiate consultations.

A regional strategy for public engagement will need to include at least three elements:

1. A carefully outlined argument for such a model.
2. A strategy of engagement with groups within the community.
3. Clarity about and consistency with the normative procedural standards for good deliberation.

The argument for the model will stem from the understanding and commitment developed in recommendations A2 and A3. It should be clear about the various reasons above for the engagement. It should clarify its commitment to the various rationales and incorporate these in appropriate kinds of ways. The strategy should include elements for dealing with D2, D3, and D4 below. For each it should respond to the design questions that Fung articulates, specifically the questions:

- What work is the forum meant to do?
- Who should participate in the forums?
- How should these individuals be recruited?
- What issues will the participants discuss?
- How will the discussion be structured?
- How often will the group meet?
- How will participants' stakes in the conversation be accounted for?
- What decision-making authority will the group have?
- At what stage of the decision-making process will the group convene?

### *D2 & D3: Identification and refashioning existing forums & creating new forums*

These call for the identification and refashioning of existing forums where these might exist to make them more deliberative and the creation of new deliberative processes within the public sphere. In developing new forums of engagement and seeking to help existing forums become more deliberative, health regions should explicitly be guided by and strive to live up to the following procedural standards:

- Participants should have confidence in their ability to influence the decision process such that they feel it worthwhile to continue in the process.
- The public should have access to the types of complex decisions that need to be and are regularly made.
- The public should be supported in developing an understanding of the relevant information needed to make such decisions.
- Participants should expect to have their perspectives meaningfully engaged.
- To the extent that these ideal characteristics of the public sphere are realized in a given minipublic, these minipublics should be empowered with the authority to make decisions.

- It should treat different voices with respect, such that the reasons of all should be heard, understood and responded to in it.
- There should be opportunity to review and revise past decisions.
- There should be room for all types of reasons to be engaged, including dogmatic perspectives that holders are likely not going to change.
- The approach should always be to seek solutions that respect a broad range of value perspectives and the conditions for fair moral compromise pursued.
- Where fundamental disagreements – deep conflicts – persist, these differences should be handled with mutual respect and the goal should be to identify these and continue to meaningfully engage these, even as time-sensitive decisions must be made.
- There should be room to question the assumptions behind decisions and the conceptual framework against which decisions are being made, to challenging prevailing discourses. Changing the agenda and revising the questions should be possible.
- There should be intentional consideration of what forms of expression are acceptable and room for different types of communication should be ensured.
- To the extent that the public sphere is seen as decentred, leaders should engage the reasons delivered by these moments of engagement and respond to these in the decisions that they make.

### *D4: Addressing inequality*

The mandate of the facilitators of the public sphere includes intentional effort at identifying where political domination occurs, and finding ways to increase access to the deliberative sphere and empower these populations. Leadership should explore areas where affected parties are not connected enough to have access to decision processes and actively work to overcome this. Leaders should adopt Young's test for inclusion. Again this test requires that "If a public debate usually refers to a social segment in the third person, if that social segment rarely if ever appears as a group to whom deliberators appeal, and if there are few signs that public participants in deliberation believe themselves accountable to that social segment, among others, then that social segment has almost certainly been excluded from deliberations." (Young, 1999 p. 157.)

When such groups are identified, leaders should:

- Focus on the capacity of such individuals to use resources, procedures and opportunities for effective communication.

- Find ways of providing such groups with access to the decision-making process, either by creating new deliberative public spaces or reshaping existing ones.
- Identify and support existing sub-public spaces – spaces where sub-groups of the polity sharing some commonality are able to pool their resources of political deliberation and engage issues on a smaller scale.
- Not see these as sources of dissension to be marginalized, but instead seek to nurture these spaces and find ways of merging these streams into the broader avenues of discussion of social issues.

### *D5: Developing an interim public engagement approach*

Until a strategy is in place, an infrastructure is developed, and the broader public sphere is effective, leaders should employ a short-term public involvement strategy. In particular, leaders should determine ways of linking their decisions to moments of public engagement. These could involve the creation of minipublics (appropriately structured to meet the standards of Empowered Participatory Governance of Fung and Wright (2003)) to address specific issues such as managing patient flow through a system or even regional budget redesign. Or it could include much more humble approaches such as meaningfully open board meetings, structured conversations with community groups, focus groups, engaging community health councils (Gibson, Martin & Singer, 2005) and the like. Careful attention would have to be paid to ensure dialogue in these forums meet deliberative standards. The output of such sessions need not be binding as neither would individual forums be representative, nor representation be achieved through the decentered public sphere (not yet in place).

As part of this strategy, regional leaders should also help the communities they serve to think about the values immanent in the system and engage in deliberative dialogue around value tensions where they exist. This should include dialogue around how these values are honoured in the context of the Canadian health system, and where they are not honoured. The goals of this dialogue would include helping the community understand what is at stake, deepening the moral discourse around these values in light of the rich context, and determining community value commitments for uptake in actual decision-making.

Specifically, regional leaders should facilitate deliberation about:

- The global implications of the commitment to equity.
- The tension between high quality services and universal access.
- The significance of the literature on the determinants of health.
- Canadians' value commitments in light of this evidence.
- Canadians' vision of what healthy and meaningful life looks like.
- What the health system can do to facilitate advancement of health status.

A well developed short-term engagement strategy will likely transition into the region's long-term public engagement effort.

### Cluster E: Staff Engagement & Strategy

The values of health care professional integrity and accountability lead to an operational cluster about staff engagement. The recommendation from this cluster is that regional leadership should have in place a staff engagement philosophy and systematic strategies for facilitating staff engagement in the decision process.

This cluster involves two key recommendations:

1. Develop a staff engagement philosophy.
2. Develop a staff engagement strategy.

#### *E1: Staff engagement philosophy*

This philosophy and collection of strategies should recognize the value of staff as experts about the facts that will inform many of the decisions made, including understanding of the context within which decisions are implemented. It should also respect the role of staff as professionals with a responsibility to ensure the ethical care of patients and as moral agents with their own values at stake in the moral enterprise of health care.

#### *E2: Staff engagement strategy*

The strategy for staff engagement should balance providing an appropriate role for physicians and staff to be involved in decision-making with not over privileging their perspective because of their technical expertise. Processes of engagement can include the use of day-long workshops to participate in such broad decisions as resource allocation, direct involvement on planning teams, again focus groups, and the like.

Possible tensions may arise between this cluster and those related to leadership self-understanding and public engagement. That is, as individual leaders and teams struggle to understand their own value commitments, and as they strive to meaningfully live up to the considerations of public engagement and staff engagement, they may find that these are in tension and the question will arise as to how this tension is to be resolved. This speaks to the importance of having a comprehensive and well thought out engagement philosophy on the part of health regions. The philosophy should anticipate the possibility of these tensions arising and should provide direction, that itself will be based on value commitments and that itself will have to live up to the decision criteria, for how these differences are to be resolved.

## Purposive Action as the Art of the Possible

In this section I will describe the kind of challenge one might anticipate to the above recommendations and suggest responses.

The commitment of leadership to the project is crucial. Were I to present this approach to colleagues in senior management within a health authority, there is a concern that leaders might respond saying this all sounds very nice in theory, but it is simply not practical – to pursue such a course would be a gamble at best – from both a resource and a political point of view. Politically, if it did not work, instead of building trust it could go a long way to undermining it in all of the relationships important to the region – relationships with government, with staff and physicians, and with patients and the community. From a resource perspective, this project would consume inordinate amounts of time, energy and money. When resources are already so scarce, this would be an unwise use of healthcare dollars. Finally, the challenge of complexity would likely be made. That is, it would be argued that allocation decisions are at base technical medical and economic questions requiring much experience and expertise. Were the public to somehow get involved, they would simply not be able to reach the knowledge thresholds that this decision-making would require.

In terms of the political risk attached to the approach, it is true that efforts at engagement that are insincere or do not meaningfully honour the perspectives of participants would lead to greater mistrust (Abelson, Lomas, Birch, & Veenstra 1995, Abelson, Eyles, McLeod, Collins, McMullan, & Forest, 2003). But this does not caution against meaningful engagement. Rather it suggests that insincere engagement, or exercises in "window dressing" that don't live up to deliberative standards and don't acknowledge or act on the outcomes of the deliberations should be guarded against. There is a growing mistrust of policy-makers in the public (Nevitte, 2002). The risk of further disaffection is likely far outweighed by the prospects of building trust if engagement is undertaken with the right intention and the appropriate degree of rigour.

When it comes to questions of appropriate use of resources, the first thing to be said is that there are many other non-healthcare service delivery initiatives that are currently funded by health authorities. Programs of organizational development, strategic management and change initiatives all seek to support the organization negotiate the challenging modern healthcare environment. So a precedent has been set for this kind of work. More importantly, as a programmatic candidate for resource allocation, the question can be asked: By what legitimacy is the decision for or against supporting such an initiative made? That is, the proposal for support itself can be used as an opportunity to facilitate dialogue around the issue of legitimate and just policy-making.

In terms of complexity, per the discussion in Chapter Two, it is important to recognize that the complexity of health system decision-making does not preclude meaningful democratic participation. That is, the assumptions of hypercomplexity do not hold in this case – a degree of complexity that makes meaningful public input impossible is not inevitable.[33] While complexity is both necessary and valuable in order to allow resource allocation policy-making in efficient and time-sensitive ways, a democratic complexity wherein regular forms of meaningful public input into the allocation policy-

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[33] Sue Sherwin (1998) has argued, though in different language, that the problem of hypercomplexity is one of the barriers to the respect for individual autonomy in the health system. That is, because many resource allocation decisions are taken out of the hands of patients, choices that patients are afforded are limited to the extent that genuinely autonomous decision-making is not possible in this context.

making process are woven into the policy-making process is both possible and necessary for such policies to be democratically legitimate. As Fung (2003) suggests, "while there may be other, normative grounds for objecting to strong minipublics, experience shows that the frequently encountered ground of impracticality is less persuasive than commonly thought."

The discussion of what it means for policy decisions, such as resource allocation, to be democratically legitimate will likely be constrained early on by the fears of the decision-makers as they journey into unfamiliar territory. Fears of losing control of a process, repercussions from their political masters, and loss of their personal domain of authority will not easily be balanced by the promise of more ethically sound decisions. Although there is a great deal of cynicism in the healthcare world in Canada at the moment, there is also an inspiring amount of hope. More importantly, decision-makers are at this point in history looking for support in making the difficult decisions they are faced with. There is a growing understanding that the nature of the decisions being made have an ethical dimension and have important implications for the integrity of those who are governed by these decisions. The growing market for bioethics personnel in the Canadian health care field attests to this. This leads me to believe that if cast in the right light, regional leadership may well accept the merits and value of this approach.

I have now established the philosophical-normative criteria for good decisions and set them in the form of operational recommendations for leaders. Next I turn to the practical dimension of my research project. Here I explore how to help leaders understand and act on these recommendations. In the next chapter I explore the world of the healthcare leader and the literature on decision-support tools. Based on these sources I develop a sixth cluster of operational recommendations concerning the utility of such instruments. I then use the six clusters of recommendations and use them to evaluate two prominent approaches for supporting healthcare decision-making.

# CHAPTER FIVE: DECISION SUPPORT AT THE LEVEL OF PRACTICE

## Introduction

At this stage, we have a strong sense of what is required for system-level decisions in Canada's regionalized health system to be justified. This is based on the limits of moral theory, the possibilities and requirements of a deliberatively conceived democratic theory, and on an interpretation of Canadian values. However, a compelling defense of normative criteria will not be enough to actually make a difference. The justification will have to be presented in language that speaks to practically-minded leaders, directly address concerns that these folks have, and be supplemented by tools and resources that enable leaders to live up to the more abstract norms that I have articulated in earlier chapters. Accordingly, an important question remains to be considered: What kind of resource will effectively support leaders to make more justified decisions?

In this chapter, I first explore further the context within which decision-makers must address challenging questions. I consider where current decision-making falls short and what leaders themselves identify as the barriers and supports they experience. I then look at the literature on decision support resources for guidance on what makes a resource effective. Based on these sources, I offer a sixth cluster of operational recommendations called "utility criteria." I then examine two leading alternative approaches to supporting system-level decision-making in health care, with a view to building on their strengths and learning from their shortcomings. At the conclusion of this chapter, I will have set the stage for Chapter Six where I develop an actual decision support workbook, from initial drafting to testing with end users and suggestions for the final form that such a product might take.

## Decision-Making in the World of Health Care Leaders

In this section I consider the experience of the healthcare leader. I describe the landscape against which such people do their work, including some of the challenges they face and the resources they find useful when it comes to decision-making.

### *Method of analysis*

The claims I develop in this section are drawn from literature on leadership at the meso level in healthcare. They are also drawn from my experience working within the health system. They are not drawn from the literature on leadership in general.

A challenge for developing this section is that there is not a rich literature available that provides insight into the world of the regional healthcare executive or manager. And while research has been conducted into the decision-making of leaders in the business world, how leaders in health care make decisions and what they find useful has remained largely unexplored (Releeder, Martin, Keresztes, & Singer, 2005).[34] I am able to draw on studies conducted with CEOs and other leaders in the provinces of Ontario and Alberta regarding their views on priority setting (or resource allocation in the language I have used to describe this experience).

These claims are also tested against my own personal experience working with leaders in Canada's regionalized health system over the past decade. In that time I have served the Provincial Health Ethics Network of Alberta (PHEN), Providence Health Care, and Fraser Health. I have had occasion to work with almost 20 health authorities, mainly from the provincial health system but also the federally mandated Correctional Services Canada. I have worked with members of authority boards and CEOs through to middle and unit managers. With all of these organizations I have been involved with providing support to leaders facing difficult system-level issues. The issues raised have ranged from making publicly owned care facilities available to private users during off hours and developing human resource guidelines, to considering whether caregivers in a mental health facility ought to be able to receive gifts from patients and deciding whether or not to perform meconium testing on newborns of mothers suspected of using narcotics. The administrative departments I have worked with include finance, communication, and human resources. Clinical areas include acute care, extended care, residential care, home care, and population and public health.

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[34] In part, this is likely due to the fact that regionalization in healthcare is a fairly recent development, taking place initially in the mid-1990s and continuing to be refined even today.

I begin with a heretofore unarticulated assumption: that there are problems with the status quo in decision-making.

### *Where current decision-making falls short*

An important claim that I have left implicit so far in my argument is that as it currently stands, system-level decisions in health care are in fact not well justified according to the normative criteria I have set out. There are at least two grounds for this assumption. First, the making of system-level decisions in regionalized health care today is not done in a transparent, systematic, values-driven way and includes little or no public consultation. For example, when it comes to questions of priority setting, it is suggested that decisions are made in an ad hoc manner (Teng, Mitton, & MacKenzie, 2007) and that the key determinants of decisions made include historical and political reasons (Mitton and Donaldson, 2004a). As one leader is reported to have said, "It's a squeaky wheel process. Whoever is able to more clearly articulate their problem, or lobby for their group or, through some other form of power and influence, impact whatever process is in place that year will come out with some outcome" (Teng et al., 2007, Results, Current Priority-Setting Processes section). Decision-makers often claim decisions are based on evidence or medical need but rely on non-need-related criteria for their choices (Walton et al., 2006). In a study of 160 hospital Chief Executive Officers, or their designates, in Ontario, only 60% of respondents thought priority-setting decision-making in their hospitals was fair (Reeleder et al., 2005).

The second reason to suggest that leaders require support for justified decision-making is that leaders in the system have identified this as an issue and are asking for support in making such decisions. For example, Gibson et al. (2005) report that, consistent with survey reports that leaders are asking for help with how to make resource allocation decisions, since 2000 ethics staff at the University of Toronto Joint Centre for Bioethics "have observed a significant increase in requests for advice from senior managers and board members across Canada about how to set health service priorities fairly and how to implement ethical decision-making processes for resource allocation" (p. 51). I'll say more about the requests leaders make over the next few sections.

### *The context of the regional decision-maker*

Leaders seem to have a fairly clear sense of understanding about their own role and the scope of their authority. However, this self-understanding is not always consistent. In terms of their role, leaders report that this includes responsibilities around:

- fostering a vision
- creating alignment between the community, the board, the senior team, medical leadership, other institutions and partners in accepting the vision
- developing relationships
- living the organization's values, and
- creating effective processes by which stakeholders within and outside the system can abide. (Reeleder et al., 2005)

This is distinguished from the role of middle and lower management, whose responsibility was seen as limited to ensuring the implementation of the region's goals effectively and efficiently (Ibid.). Leaders also believe that it is their job to make hard decisions at the end of the day (Ibid.).

In terms of actual resource allocation decision processes, the overall approach seems to involve clinicians developing program priorities and then having these advocated up the organization's hierarchy. Then the process enters a shadowy passage: "We have had input but it has been very much directed by your supervisor, then it goes into this black box of the executives and it comes back out to you" (Mitton and Donaldson, 2000 p. 44). History is powerful. In other words, decisions made in the past are often continued forward without much more critical review (Mitton and Donaldson, 2000 & 2003a). They are often based on anecdotal evidence and public opinion is not consulted. Decisions are based on historical trends, responding to the crisis of the day, negotiation across the executive table or through nor formal process whatsoever. It seems that as with life sustaining treatment, it is much more difficult to withdraw it than to not initiate it in the first place. In spite of this, studies suggest that regional leaders believe priority setting decision processes operate reasonably well for the most part (Mitton & Donaldson, 2000).

Leaders identify a number of barriers that impede good decision-making. For example, senior healthcare leaders believe staff overestimates the degree of freedom they have in decision-making (Releeder et al., 2006, Maddalena, 2006).[35] Another particularly challenging constraint has to do with certain relationships that are crucial. These include with members of the board, with unions, and with professional organizations. In one report of interviews with regional CEOs about priority setting, the authors describe a CEO's views of the importance of her relationship with and limitations of working with physicians: "it is vital that the leader is able to enlist their cooperation in her priority setting pursuit. As one CEO put it bluntly, 'you have a bunch of people who are not our employees who spend most of our money through their decisions'" (Releeder et al., 2006 p. 29) "Closed-door decision-making" is also seen as one of the major hindrances to effective decisions (Mitton and Donaldson, 2003b). The political nature of decision-making in healthcare is seen as a real challenge, because even when it is argued that there is good evidence to buttress a position, it will be trumped by what are called political considerations (Ibid.). As well, political sensitivity leads to discomfort with honest communication and analysis, which are seen as central to good decision-making (Ibid.). In addition, there is often insufficient time to assess competing priorities and to make informed choices. The constant sense of crisis, the mentality of turf protection that often pervades clinical and administrative settings, the challenge of comparing programs with

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[35] I also offer the personal anecdote: I once attended a leadership workshop offered to leaders throughout a health region and found myself in a small group exercise with two other individuals – a senior vice-president (VP) and the manager of a small nursing unit in a community hospital. The exercise invited us to describe the constraints that impacted our ability to make decisions based on our personal sense of right action. The nurse manager described how tied her hands were when it came to making decisions. She mentioned the limited number of staff she had to come and work on her unit, the limited resources to pay staff for attending meetings on the unit and to advance their own professional training, and the difficulties of working with a revolving door of physicians, all with authority to make decisions, but each with their own personal decision-making style and value set. A few days after the session, I bumped into the VP in an elevator and we reflected on the workshop and particularly on our small group discussion. What struck the VP was not the degree to which the nurse manager was constrained. The moral distress experienced by nurses has been well documented and is becoming much better understood within the health system generally. Instead, it was the sense the nurse had about the degree of authority and freedom that the VP had which was so out of touch with the VP's own sense of reality. The sentiment of the VP was that the nurse had no idea just how little room there was for the executive to make choices she really believed in. From the region's detailed strategic plan, the Board's priorities, and the government's ever-changing and expanding to do list, to meeting the needs of various professional groups, primarily physicians, and serving the needs of other members of the executive, the VP saw the range of choices available to her as tightly bound.

vastly different goals and serving very different populations, inadequate data, non-transparent processes, inappropriate incentives for physicians, public demand and poor communication are all seen are features that exist in the current climate that hinder good decision-making (Mitton & Donaldson, 2000, Mitton & Donaldson, 2003b).

A number of features that support good decision-making are identified in the literature as well. Reporting on day-long priority-setting workshops with board members and senior leaders at three Canadian academic health sciences centres, Gibson et al. (2004) report that leaders identify ten important process elements for priority-setting to be fair. These are:

- Confirm the strategic plan
- Clarify programmatic architecture, including program groupings and definitions
- Clarify board and management roles and responsibilities
- Determine who will make priority setting decisions and what they will do
- Engage internal/external stakeholders
- Define priority setting criteria and collect data/information
- Develop an effective communication strategy
- Develop a decision review process
- Develop process monitoring and evaluation strategies
- Support the process with leadership development and change management strategies.

The most consistently reported enabler for good decision-making is a formal decision process that is

- Open, inclusive and collaborative
- Uses common language and conceptual frameworks that can be understood by everyone so that fair argument is possible
- Enables communication and mutual understanding between managers and clinicians
- Creates comfort and safety for leaders to engage in frank discussion and to challenge each other respectfully
- Enables the buy in of physicians
- Is systematic, explicit and transparent
- Makes room for good data, including outcome and efficiency studies

- Helps to offer justifications for decisions
- Is predictable with clear expectations (Mitton & Donaldson, 2000 & 2003a, Reeleder et al., 2005).[36]

> *When [senior management] say [to managers] why did you put $50,000 in there, sometimes [managers] have a really difficult time rationalizing why they did it, especially when it's political. But a good priority setting tool will help them defend decisions that were made.* (Mitton & Donaldson, 2000 p. 53)

Decision-makers also find it helpful and important that decision criteria are explicit and agreed upon before resource allocation decisions are made (Releeder et al., 2005).

The role of leadership and institutional culture is seen as crucial to good priority setting (Singer et al., 2000, Martin, Pater, & Singer, 2001, Gibson et al., 2006, Peacock, Ruta, Mitton, Donaldson, Bate, & Murtagh, 2006). Good leadership is perceived to include the ability to balance power (between physicians, the board and the executive), including physicians in the decision process, establishing teams, and building trust, empowerment and delegation. It is suggested that an inclusive process where people are treated with respect and where trust is built is very valuable and could avoid the problem of having to respond to the squeaky wheel (Releeder et al., 2005). One interesting finding reported is that despite the clear appetite for decision support tools, including decision processes, leaders report not being aware that any such tools exist or where to get them from (Mitton & Donaldson, 2001, Mitton, & Patten, 2004). Other facilitators of good decision-making include a culture that supports learning and that is open to change (Mitton & Donaldson, 2003b).

The literature suggests that regional leaders seem to want public input into decision-making, but find it difficult to get (Releeder et al., 2005). Processes for community engagement are considered helpful: "the RHAs did express genuine interest in improving dialogue with the public, particularly in terms of developing broad priority goals" (Mitton and Donaldson, 2000 p.55). In particular, being open and transparent with the public through communication about the process of decision-making and the criteria to be used was seen as very important (Reeleder et al., 2005).

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[36] Singer, Martin, Giacomini and Purdy (2000) found that decision-makers believed the quality of this internal process was key to the fairness of the outcomes.

In summary then, according to decision-makers, a decision process will be practically useful if it is:

1. Systematic:
    - Is formal, explicit, and transparent
    - Makes fair argument is possible
    - Helps to offer justifications for decisions
    - Is predictable with clear expectations
    - Enables breaking through a context of inadequate data, non-transparent processes, and inappropriate incentives for physicians
2. Inclusive:
    - Uses common language and conceptual frameworks that can be understood by everyone
    - Is open and collaborative
    - Enables healthy communication between managers and clinicians
    - Enables physician engagement
    - Enables public engagement
3. Sensitive to the context
    - Is aware of the highly political context of decision-making in healthcare
    - Can be used within time pressures decision-makers face
    - Enables comparing programs with vastly different goals and serving very different populations
4. Has a clear role for good evidence
    - Makes room for outcome and efficiency studies

Elements of these four dimensions are echoes of the recommendations in the five clusters of described in Chapter Four, based on the normative work in Chapters Two and Three. The call for transparency and systematization of decision-making resonate with Cluster A: Understanding and Key commitments and Cluster B: Decision-Making. The call for inclusiveness is consistent with the need for a clear language for discussing issues in Cluster A. And it overlays with Cluster D: Public Engagement and Cluster E: Staff Engagement. The need for sensitivity to context and having a clear role for evidence evaluation could be built into Clusters A and B. At this point I introduce my sixth set of operational recommendations – Cluster F: Utility Criteria. I recommend that decision support tools should aim to be systematic, inclusive, sensitive to context, and have a clear role for evidence. However, in light of the overlap described above I do not include all four in a sixth cluster of recommendations I offer. Instead I carry forward the two recommendations not fully captured in previous clusters: sensitivity to context and having a clear place for evaluating evidence. I add recommendations to this cluster from a review of the literature on support tools. I turn now to that discussion.

## From Wizards to Frameworks: Literature on Decision Support Resources

### *Different types of decision support resources*

Decision support instruments can take a variety of forms that include presentations, workshops, computer software and web-based support materials, and decision-making manuals. The literature on effective decision support resources is very lean. Conole and Oliver (2001) suggest that these resources form a continuum with wizards at one extreme and decision frameworks at the other. Wizards are software tools that actually make decisions on behalf of the user. They ask for certain information, process this information through algorithms that usually remain hidden, and then come out with a decision for the user. "As a result, they are relatively easy to use, but are restrictive in the range of outputs that can be achieved, and allow very little engagement with issues or response to the values and assumptions built into the system" (Ibid. p.327). Clearly such wizards would not be able to provide appropriate decision support in the context we are considering, as they do not help decision-makers approximate the standards of ideal deliberative processes articulated in Chapter Four in the least.

Frameworks provide a theoretical overview of an area but can offer little direction on how to apply the theoretical concepts to the context in question. Such frameworks provide a point of reference for the decision-makers, but little other support. One might think of the principlist approach to bioethics described in Chapter One as a framework in this sense. Like the concerns raised against principlism, the trouble with frameworks is that they both underdetermine right action (by not identifying appropriate principles to guide decision-making) and they are silent on the types of processes required to arrive at decisions that would be compelling to members in a pluralist society.

Conole and Oliver (2001) suggest that between these points on the spectrum lie such resources as toolkits, checklists and guidelines. They define toolkits as

> *more structured than frameworks; they use a model of a design or decision-making process, together with tools provided at key decision-making points, to help the user engage with a theoretical framework and apply in the context of their own practice. Each of the tools that is drawn upon as the user works through the process model is designed to help the user to access a knowledge base in order to make informed decisions. The format of the toolkit means that they can be used in a standard, linear fashion, or can be "dipped into" by users whose level of expertise is stronger in some areas of the design process than others.* (Ibid. p.327)

It would seem, then, that it is in the area of "toolkit" that an appropriate decision support resource for decision-makers in health care working at the system-level will be found. Such a resource would be much more inclusive and engaging than a wizard and much more supportive and process-related direction giving than a framework. Mitton and Donaldson (2003c) echo this finding, also calling for a toolkit for supporting leaders in making decisions about priority-setting.

Other decision support resources, like presentations and workshops, would have to be used with limited numbers of people at a time and will require trained, or at least oriented, human resource support. These vehicles, like web-based tools and computer software will require the development of basic content in terms of both a theoretical framework and techniques for helping users engage the framework. To support such resources and to facilitate widespread circulation, it seems to make sense to first capture the content of these instruments in the form of a manual or workbook. This would likely be easily translated into any of the other vehicles mentioned above.

### *Importance of interaction*

If a decision support resource is designed for users to use independent of additional support, then it will be important for the resource to be interactive. This is important to minimize the user's sense of isolation, to personalize the knowledge base and bring the author closer to the user, and to help the user get a deeper understanding of the knowledge base – to engage and challenge ideas, rather than memorizing information and following instructions (Commonwealth of Learning, 1999). An interactive approach also help focus the learner's attention, it can help anchor new ideas to past knowledge, and it can empower users to try ideas out for themselves, applying them in their own context (ibid.). It is recommended that to foster interaction, learning strategies must be relevant and have objectives that align with the goals of the user, be challenging and interesting, and include a variety of approaches to suit diverse learning styles (ibid.).

Methods of interactive learning include:

- Activities that focus a learner's attention on the subject;
- Activities that encourage learners to reflect on their existing knowledge and experience that may be relevant to the subject;
- Activities that suggest ways in which learners can apply what they are learning;
- Problem solving activities;
- Project work; or
- A question and answer approach, exploring a subject through a series of questions, which encourage learners to carry out their own analysis.

Techniques for helping learners to maximize learning activities include:

- Explaining why the activities have been included;
- Describing the advantages of an active approach to learning;
- Explaining the purpose of each activity;
- Highlighting the benefits that activities will offer learners;
- Integrating activities into the course assignment;
- Creating a range of types of activities; and
- Avoiding activities that require large mental leaps away from the line of thought pursued in the materials.

Whatever resource is developed, it should be interactive along the lines suggested if it is to be maximally useful. However, it is not only to maximize utility that interaction is important. If the normative standard to guide justified decision-making is to be the kind of process driven approach defended here, then it will be important for any decision support resource itself try to demonstrate deliberative engagement, modeling for users the types of questions for engagement, the language for this engagement, and the types of steps required in the engagement process.

Conole, Oliver, and Harvey (2000) also set out useful standards for any toolkit. They suggest that toolkits should be easy to use, they should be able to provide clear benefit to the users, they should be direction-giving without being prescriptive, they should be applicable to various contexts, and they should offer the user access to a reasonably comprehensive knowledge base. It is not clear how they justify these considerations, but they seem very reasonable and consistent with both the needs identified by health care leaders and, more importantly, consistent with the normative standards I have defended so far. These standards can be used to evaluate decision-support resources – both that have already been created (such as those by Daniels & Sabin and Mitton & Donaldson mentioned below) and those in construction (such as my own in Appendix B).

### Cluster E: Utility Criteria

So far, there are two recommendations in the sixth cluster of standards by which to evaluate a decision-support resource. The tools provided should:

1. Be sensitive to the context (that are aware of the highly political context of decision-making in healthcare, useful within time pressures decision-makers face, and enable comparing diverse programs)
2. Have a clear role for evidence evaluation (that make room for outcome and efficiency studies)

From the discussion in the previous section, three additional recommendations can be added:

3. The workbook should facilitate the critical engagement of the user and not lead to decisions based on values embedded within the tool.
4. The workbook should provide practical direction about decision processes and not be limited to theoretical reflection on these.
5. The workbook should be interactive and model for users what good engagement requires.

Having established this final set of criteria, I now turn to existing frameworks that concern priority-setting in health care to see what lessons can be learned from these models.

## Alternative Approaches to Decision Support

Some decision support frameworks and tools for policy-makers in health care do exist. These mainly focus on the specific area of priority setting for resource allocation decision-making. In this section I offer a critique of two competing approaches for supporting justified decision-making: Daniels' and Sabin's (2002) Accountability for Reasonableness (A4R) framework and Mitton's and Donaldson's (2002 and elsewhere) adaptation of the Program Budgeting and Marginal Analysis (PBMA) model. For each, I first review the approach and then evaluate it against the operational recommendations set out in Chapter Four and the practical standards elaborated earlier in this chapter. I take the concepts and tools I am trying to develop in this dissertation to be in the same general category as these approaches. One of my goals is to learn what I can from these approaches, capitalizing on the strengths they offer. The weak points of these approaches will also have particular implications for my own method. Another goal is to identify the challenges these approaches are exposed to and seek to address these in my own model.

### *Accountability for Reasonableness (A4R)*

The leading account of the standards for fair processes in meso-level decision-making comes from the influential work of Daniels and Sabin (2002) called Accountability for Reasonableness (A4R). Like other authors in the deliberative tradition, these authors argue that the reasons underlying any public health policy should be publicly accessible and acceptable to fair minded people. They argue that policies can be morally legitimate if they meet the following four criteria.[37]

The first of these conditions is *publicity*. A resource allocation policy meets this condition if the content of the decision-making is transparent to all those affected by it. It

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[37] Importantly, Daniels and Sabin are writing the context of the American health system, and the program level decisions they seek to support are those made by health maintenance organizations.

is about making clear the value commitments taken into account by the decision-making body. Making the rationale of a decision publicly accessible is important because it allows for greater reflection to be brought to bear on the decision in question. This leads to better decisions both in the short and the long term. In the short term, those affected by the decision will be more likely to accept the decision if they see the thoughtful rationale and process by which it was achieved. As well, a process that is open to scrutiny is more likely to avoid faulty reasoning. In the long term, as it becomes clear that the authority is committed to careful, thoughtful, and consistent policy-making, greater trust in the decision-making authority will be inspired. In addition, a sort of case law for handling policies will emerge over time that will provide strong reflective foundations for handling new policy questions as they arise. To meet this condition, when a decision is made a regional body would need to ensure the rationale for the decision is available.

The second condition is that of *relevance*. To meet this condition, the reasons that are given for a policy decision must be such that those affected by it see that the reasons are both relevant and appropriate for the policy in question. This condition does not require everyone to agree on the reasons for the policy decision. The thought is that for a resource allocation decision to be acceptable, fair-minded individuals must simply be able to accept that the reasons given for the decision are reasonable. The goal is to weed out inappropriate justifications for policies, such as religious perspectives that would not be shared and that many who are affected by the decision would find unreasonable. Fish's (1999) views on abortion would not be permitted into the arena – and certainly the active inclusion of those with dogmatic views, no matter how popular in the community, would not be required.[38]

The third condition is that of *revision & appeals*. This condition calls for an appeals mechanism to be created. This will encourage public participation in the policy-making process and bring a multiplicity of perspectives to bear on the issue. This, in turn, will lead to more informed, thoughtful, and acceptable policy solutions to a problem. This condition is sensitive to the fact that there is not much point to having access to the

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[38] See Chapter Two for discussion.

reasons behind a decision if you cannot do anything about it. It also speaks to the fact that there is often more than one reasonable solution to a given policy problem and the goal is to strive for the most reasonable solution in a given context rather than find one ideal solution.

The final condition demanded by this approach is *regulation*. This condition is meant to provide the backbone for the first three conditions, requiring that the three be formalized into the policy-making process. The condition serves to make the decision-making body truly accountable for making fair decisions and also to formally connect the discussions of policy-makers with public deliberations on the question at hand in a more formal way.

Daniels and Sabin's work has largely remained at the theoretical level. Gibson et al. (2004 & 2005) are advocates of the model from the University of Toronto (UofT) and have tried to operationalize it in Canadian healthcare context.[39] I will say a few words about their development and use of the model and then offer my analysis.

There are several noteworthy points about what Gibson et al. have done with the original A4R model. The first concerns their interpretation of Daniels and Sabin's four conditions. Gibson et al. recast the appeals condition as a condition of revision. Instead of a one-time appeal, the focus of is on an iterative decision process with various opportunities to engage the decision at hand. This is meant to transform what might become a legalistic and adversarial process into one that is centred on improving the quality of the decision in question (2005 p.57). Second, the focus of the original condition of regulation with enforcement is transformed into concern about good leadership and thoughtful evaluation of decision processes. Gibson et al. also add a fifth condition, Empowerment, to the A4R framework. "There should be efforts to optimize effective opportunities for participation in priority-setting and to minimize power differences in the decision-making context" (Ibid.). These reformulations suggest that Gibson et al. find the original A4R principles do not go far enough to live up to the value

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[39] While these three authors have had different experiences with the model, I will treat them as one for my purposes here.

of inclusiveness and to the ideal deliberative context defended in a strong account of deliberative democratic theory.

Gibson et al. also enrich Daniels and Sabin's approach by articulating a decision-making process. This process is called "A strategic approach to health services priority setting" and includes the following steps:

> *Establish, refine or confirm the organization's strategic plan (i.e., mission, vision, values and goals).*
>
> *Specify the responsibilities of the board and senior management in relation to the priority-setting process explicitly and upfront.*
>
> *Clarify the programmatic architecture of the organization (i.e. what services are offered and how they are grouped administratively and programmatically) and create an inventory of current health services activities (e.g. volumes).*
>
> *Assess each health service in terms of its alignment with the strategic directions and other relevant priority-setting criteria (e.g. community health needs).*
>
> *Develop a priority listing of all health services to facilitate making strategic resource allocations.*
>
> *Support decision-making with a legitimate and fair priority-setting process.* (Ibid. p.52.)

### *Analysis of Accountability for Reasonableness*

A) Understanding and Key Commitments

This cluster calls for leaders to appreciate the evaluative nature of decision-making and increase their ability to speak together about values and beliefs; to commit to a rich understanding of publicity and to the development of a public sphere around the healthcare system; and to understand the idea of democratic complexity and commit to democratizing the decision-making that happens at the system-level in the organization.

A1) appreciate the evaluative nature of decision-making and improve ability to speak together about values and beliefs

It is not clear how well A4R will help leaders to understand the evaluative nature of their work or improve the ability of leaders to speak usefully about decision criteria. It is not clear that A4R is actually meant to do this. But without it, one can imagine leaders having the kinds of confused discussions about values that Giacomini et al. (2004) describe.

A2) commit to a rich understanding of publicity and to the development of a public sphere around the healthcare system

The deepest concern I have with A4R is that the limited degree of public engagement it calls for does not yield justified decisions.[40] Daniels and Sabin's argumentation is problematic for the following reason. They tie the legitimacy of decisions in a pluralistic context to public deliberation. But the degree of public deliberation entailed in the A4R framework is so limited, it fails to deliver on the promise of justification. The consequence is that using A4R provides the patina of legitimacy to decisions that are procedurally unjust (Fleck, 2001).

A4R's focus on the values of publicity and relevance demonstrate a commitment to making values explicit; to values-based, reason-driven decision-making; and to the ideals of a deliberative decision process. However, A4R does not call for any formal commitment to deliberative ideals. In my view, A4R falls too far short of this ideal. And while Gibson et al. (2004 & 2005) do improve the model, it still does not go far enough. There are several specific deficits to the approach.

A3) understand the idea of democratic complexity and commit to democratizing the decision-making that happens at the system-level in the organization.

A4R does not reflect on the concept of democratic complexity. The model has been limited to the context of priority-setting in healthcare organizations. It recognizes the distinction between facts and values and suggests the need for fair processes to

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[40] In their application, Gibson et al. turn to procedural fairness to justify priority setting decisions because they too believe that there is no way to resolve the conflict between competing substantive moral principles in a pluralistic context. Because fair process is important and A4R offers a framework for thinking about this, they seem to have opted to follow it. Gibson et al. do not develop the theoretical underpinning of A4R, instead relying on Daniels and Sabin's argumentation.

resolve value difference in pluralist societies. However, this is limited to the operational context of resource allocation.

B) Decision-Making

This cluster calls for leaders to review and revise the internal decision dynamics at the region; to directly consider substantive values immanent in the Canadian context in their decision analysis; and make transparent the decisions made, the value-trade-offs these involve, and the justification for this balancing.

B1) Review and revise the internal decision dynamics at the region

The introduction by Gibson et al. (2004) of concern for good leadership and thoughtful evaluation of decision processes aligns with the importance my analysis places on modeling ideal communication. Gibson et al. have also done work with regional leaders in various Canadian healthcare institutions and organizations. Among the items in the list of key process elements that they report decision leaders felt were important in a legitimate priority-setting process are: clarifying board and management roles and responsibilities, determining who will make priority setting decisions and what they will do, and supporting the process with leadership development and change management strategies. While Gibson et al. have begun exploring what leaders' views about good leadership are, they haven't provided a practical analysis of what is required by good leadership or tools for how good leadership ought to be demonstrated in the decision-making context. My sense is that leaders will require a much more fine-grained analysis of things to look for in relationships amongst leaders in decision-making than is provided by either Daniels and Sabin or Gibson et al.

B2) Directly consider substantive values immanent in the Canadian context in their decision analysis

In its application, Gibson et al. indicate that in developing criteria for priority setting using A4R, leaders reference the mission, vision, values, and strategic plans of their organizations. In this way, the process does facilitate reflection on values immanent in the context. However, it does not formally call for review of substantive or procedural values embedded in the Canadian national context within the decision process. A looming question is, how are the values of these organizations themselves legitimized?

B3) Make transparent the decisions made, the value-trade-offs these involve, and the justification for this balancing.

Daniels and Sabin do not offer systematic processes for operationalizing A4R, however GMS do. This process is listed but not described in too much detail. A question for A4R is whether by itself this level of support can effectively direct change. I'll illustrate this worry with a parallel concern in the landscape of Canadian health care. Every health region must undergo accreditation by the Canadian Council for Health Services Accreditation (CCHSA, 2002) and these standards have begun to call for greater awareness and incorporation of organizational values and resources for resolving tensions where value disagreements exist. However, experience suggests that the standards by themselves, do not provide sufficient and appropriate direction on what the standard is, why it is important to meet, what is practically required for meeting it, and how organizations might practically go about creating the changes necessary to meet the standard. Leaders and organizations are thus left frustrated and floundering about how to move forward. A4R offers a framework for decision-making about priority setting. But how should it be used? What is one to do with the theoretical framework? Without supplementary tools the worry is that A4R does not offer enough practical direction for end users.

Another concern is that this approach revolves around a narrow understanding of what count as good reasons within the policy debate, serving to unjustly exclude relevant voices in the allocation policy discussion. It is exposed to the very kinds of concerns that are raised by Young (1996 & 1999, and Mansbridge (1999) – about the exclusion of voices and perspectives that are the most vulnerable in the deliberative arena. A better approach will attend to and provide recommendations for empowering marginalized perspectives.

C) Decision Follow-Up

This cluster calls for leaders to anticipate and support decision follow-up with education plans to ensure that those who need training to implement decisions have this; communication plans to ensure that those that need to know about decisions are made aware of the relevant information; sustainability plans to ensure the long-term implementation of well-considered and justified decisions; downstream support plans to assist those who will be put in morally compromising situations as a result of the upstream decisions; and evaluation and review plans to ensure that the actual consequences of a decision taken match those anticipated, and to take advantage of any changes in facts or values that may arise.

Also on the list of key process elements Gibson et al. (2004) report from their work with decision are: developing an effective communication strategy, decision review, and monitoring and evaluation strategies. Clearly decision follow up is on their radar. But as with many of the above points, what is absent and what could significantly improve the utility of their approach are practical tools for meeting these decision process elements.

Education plans. A4R does not call for formal education plans in recognition of the value of governance and sustainability. This may be implicit in the review of the decision downstream.

Communication plans. Gibson et al. highlight the importance of a strong communication strategy and provide clear direction on the parameters of this communication. They highlight certain vehicles of communication (staff forums, newsletters, visits from organizational leaders). They distinguish passive communication (published material) from active (involvement in workshops and discussion forums) and favour the latter. They see communication as relating both to effectiveness and to publicity.

Sustainability plans. Again, A4R does not call for formal sustainability plans. This may be implicit in the review of the decision downstream.

Downstream support plans. The approach is silent on the moral agency of healthcare professionals affected by resource allocation decisions. It does not offer direction for supporting this within the decision process.

Evaluation and review plans. The conditions of decision revision and appeals in the A4R framework resonate strongly with this criterion. Singer et al. found that decision-makers charged with allocating acute care resources felt that opportunities to appeal their decisions was a key element of fairness.[41] The A4R model enables this perception to be highlighted.

D) Public Engagement

This cluster calls for leaders to develop a philosophy of public engagement, including the identification and refashioning of existing forums where these might exist to make them more deliberative; the creation of new deliberative processes within the public sphere and exploring areas where affected parties are not connected enough to have access to decision processes and actively seeking to overcome this. It also calls for developing an interim public engagement approach for use until the broader public sphere is effective.

A4R provides a broad discussion of the importance of consultation and deliberative engagement of the public. This is an important step in the journey towards more justified decision-making. However it does not engage the issues and complexities of consultation with the different publics. As well, they treat the process of consultation as "one off" in a given decision question.[42] It does little to enhance the consultation infrastructure I argue is necessary for justified decision-making in general at the system-level in Canadian health care. And it falls prey to concerns about representation in the consultation mechanism for any given decision. GMS are much more concerned with this and move in the right direction with their criterion of empowerment. However they still

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[41] Singer et al. (2000) found that decision-makers believed the quality of this internal process was key to the fairness of the outcomes.

[42] Each of the examples they describe involves a specific stakeholder engagement exercise that is tied to a specific decision (Gibson et al. 2005, p. 54).

see this in very limited terms. Again, neither approach entails a formal responsibility to build a strong public sphere around health care. This will have to be an important part of a support tool that aims to live up to the standards I have articulated.

### E) Staff Engagement

This cluster calls for leaders to develop a staff engagement philosophy and a staff engagement strategy.

Defenders of A4R treat the engagement of internal and external stakeholders as one enterprise. They offer some defense of the importance of consultation and point to various mechanisms for engaging physicians and staff and the public. A fundamental problem with handling this crucial issue in this way is that it diminishes the importance of both, in particular public engagement.

### F) Utility Criteria

This calls for processes that are systematic and transparent, inclusive, sensitive to the context, and with a clear role for evidence evaluation; that facilitate the critical engagement of the user and not lead to decisions based on values embedded within the tool; that provide practical direction about decision processes and not be limited to theoretical reflection on these; and that are interactive and model for users what good engagement requires.

#### F1) sensitive to the context

The approach would meet the criteria of sensitivity to context as it fits fairly easily within the culture of program-level decision-making described above. That is, existing decision-making processes need not be altered significantly to accommodate Daniels & Sabin's four criteria. This makes it more likely that decision-makers in this area, if convinced by the argument behind it, might take up their approach. Doing so would require that more attention be paid to the reasons underpinning certain policy decisions, the making public of the rationale for these decisions, and the creation of formal appeals mechanisms.

F2) clear role for evidence evaluation;

The publicity condition is meant in part to facilitate critical reflection on evidence. On one hand, because decisions and their assumptions are being made public, decision-makers will be vigilant to get the facts right. On the other, the fact of this publicity will expose incorrect beliefs or poor evidence to challenge. The revision and appeals condition of A4R is meant to allow decisions to be reconsidered in light of new evidence. This in principle creates a role for evidence evaluation and thereby honours this criterion. The difficulty is that the extent to which this happens is determined by the extent to which decisions are actually made public. Because the degree of transparency is limited, the opportunities for the best evidence to guide decisions are similarly diminished.

F3) critical engagement of the user and not lead to decisions based on values embedded within the tool

Because the demands for transparency made by A4R are low and because in practice it appears that decisions and rationale are made transparent to very small circles, the approach favours reasons that leaders themselves identify and favour. A4R does not include resources to help leaders critically engage and challenge these views. While doing so will still not lead to democratically legitimate decisions (as the public sphere is still absent) this would increase the legitimacy of decisions, even if only marginally. A good tool should have these kinds of resources.

F4) provide practical direction about decision processes and not be limited to theoretical reflection on these

It is difficult to say whether A4R meets this criterion. In some small examples GMS suggest that A4R can be used to lead to priority setting criteria. But whether these were actually used to make decisions or not is not clear. While the A4R conditions have been used in a number of cases to evaluate past conditions, they do not appear to have been used proactively to guide decision-making processes. For example, in a number of papers, Martin and Singer use the A4R framework to evaluate the way resources are allocated in various settings (e.g. Martin, Singer, & Bernstein, 2003). If true, this may suggest that A4R represents a set of criteria or a checklist that can be used as an analytical tool to engage decisions after the fact, the way they are packaged does not lend itself to easy use up front by decision leaders.

Having said this, there is no question that A4R criteria are useful in helping to provide basic categories for the evaluation of priority-setting decisions and models. A4R was used to review the PBMA approach (considered in the next section) and was able to highlight limitations in the areas of stakeholder consultation, communication, and decision review (Gibson et al., 2006).

F5) interactive and model for users what good engagement requires

I believe that A4R is very much at the frameworks end of the continuum of decision support resources. This process is certainly helpful at a high level, but does not provide much direction on how to implement each of these steps. It does not by itself demonstrate what good deliberation looks like or how to facilitate this.

Martin and Singer (2003) find the framework useful because it provides *some* standards for evaluating priority setting. However, in these examples, it is they who are using the framework to conduct the evaluation. And the reference point for their evaluation is their personal perspectives. (For example, in evaluating the priority setting process in an intensive care unit (ICU), under the topic of relevance they evaluate the reasons given by ICU physicians against what they believe the criteria should be.) So the model as it is implemented is not about empowerment, but rather as a tool for use by experts. This does not meet the standards of interaction and modeling good decision process. While this concern is mitigated by the fact that by knowing what standards a decision is to be judged by, decision-makers will likely begin changing their decisions to meet these standards. Change will happen then to an extent commensurate with the degree of pleasure or pain of the consequences for meeting or not meeting the standard.

Gibson et al. have certainly advanced Daniels and Sabin's proposed framework in important ways. However, from a theoretical standpoint, this revision is still not robust enough to advance the legitimacy of decisions made using the process. And from a practical perspective, the kinds of directions offered are not detailed or user-friendly enough to provide busy leaders who come from diverse backgrounds working in a pressure-packed context to make practical and immediate change that will lead to long-term culture shifts in the organization.

The problems A4R runs into are in many ways indicative of the difficulties of defining decision procedures to be applied in healthcare settings. I will face these same difficulties and will have to take these seriously as I develop an alternate model.

### ***Program Budgeting Marginal Analysis (PBMA)***

PBMA is an economic framework is chiefly designed for system-level decisions around setting priorities for allocating scarce health care resources (Mitton, Patten, Waldner, & Donaldson, 2003). The framework has been used in health care since the 1970s and has gained prominence with the moves towards regionalization in Canada in the mid-1990s (Ibid.). In particular, it has been used to help make resource allocation decisions within specific programs of care at health regions in Alberta and British Columbia (Mitton, Peacock, Donaldson, & Bate, 2003, Mitton & Donaldson, 2003b).

The PBMA process involves asking five key questions:

1. What are the total resources given within a service area or health organization?
2. On which services are these resources currently spent?
3. What services are candidates for receiving more new resources (and what are the costs and potential benefits of putting resources into growth areas)?
4. Can and existing services be provided and effectively, but with fewer resources, so releasing resources to fund items on the growth list?
5. If some growth areas still cannot be funded, are there any services that should receive fewer resources, or even be stopped, because greater benefit per pound spent (or a greater fit with other defined criteria) would be reached by funding the growth option as opposed to the existing service? (Mitton and Donaldson, 2004b p. 54.)

PBMA relies on two economic principles: Diminishing marginal return or marginal analysis and opportunity cost. Marginal analysis suggests that after a certain point the value of every additional unit of resource devoted to an activity goes down. You need at least nine players for a baseball team and so the value of players one through nine is very high. But the value of every player added after that, assuming they are all of the same type (same skill level, and so forth.) will progressively go down. Opportunity cost suggests that every resource used in one application comes at the cost of not using that resource in an alternate application. Every player added to the baseball team is a player that is not engaged in some other activity. The basic idea of this approach to resource distribution or priority setting in health care is that we may be able to get more value for the program, institution, organization, or whatever the unit in question is, from each of the last dollars spent in an area by taking the money away from there and reallocating it to newer or growing programs with relatively higher impact.

In terms of process, PBMA first calls for examining how resources within a program or organization are currently being spent – program budgeting. Next the model calls for the formation of an expert advisory panel. The panel would include representatives from administration and clinicians affected by the outcome of the process. The panel could in theory include members of the public. The advisory panel would be charged with defining and weighing decision making criteria, identifying possible areas where growth would be desirable, identifying areas where resources could be withdrawn, and evaluate proposals for investment and disinvestment. The panel would then make recommendations for (re)-allocation. The panel would communicate their decisions to the organization. The process would be regularly evaluated, refined and revised (Mitton & Donaldson, 2003b).

Mitton and Donaldson (2004b) describe the application of this model to regional health authorities in Canada and the UK. The process in the British case study is described as follows:

> *The aim of the PBMA exercise was to develop clearly identifiable priorities for purchasing in the Health Board over the next 10 years. A needs assessment was first conducted to compile a health profile for the children within the Board,*

> *focusing in particular on key causes of mortality and morbidity. Policy documents were also reviewed to determine both national and regional objectives. As well a program budget was derived, containing activity and cost data for 10 broad service categories, split by various settings in which the service might be delivered – for example, one cell in the matrix was for inpatient general paediatrics, while another was for outpatient child psychiatry. The program budget helped to define child health services and identify possible areas for changing service provision.*
>
> *Views of health professionals were included through a two-staged approach. First, a multidisciplinary professional advisory panel was formed. Members were asked to generate up to 10 potential areas for service development, or investment, and 10 areas for resource release. The panel was also asked to justify their choices and specify projected health gain from proposed changes. The second stage involved a mail-out survey of health professionals working with children. Upon reviewing the needs assessment findings and the program budget, this broader group was asked to rank 10 areas for service development and 10 areas for resource release, from the service previously identified by the advisory panel, again on the basis of the expected health gain. Following this, a focus group of parents of children with health problems was established, was an advertised phone-in over a 24-day period. Suggestions for improvement of services were noted and ranked according to frequency of report. Finally, a literature review was conducted for four specific areas identified by parents and providers as candidates for service development or resource release.* (p. 93)

The Canadian exercise with the Calgary Health Region is described in this way.

> *The CHR's short term goal with this project was to aid in the development of the 2002/2003 budget across all seven major service portfolios. The longer term goal was to develop an explicit priority setting process that could be used annually as part of the business planning/budgeting cycle. The project was based on a form of social research called participatory action research, which has as its primary aim to instill change within an organization. At the core of the process was an advisory panel which was comprised of senior management team of the health region. This multidisciplinary group of clinicians administrators and other financial personnel were charged with developing a list of service growth investment options, as in question 3 in box 4.1, and, in order to fund these investments, lists of efficiency/productivity and service reduction options (questions 4 and 5 in Box 4.1). The panel then assessed the various options and made resource reallocation recommendations, based on a set of pre-defined, locally generated criteria. The step by step process is outlined in Box 7.1.* (p.96)

Mitton and Donaldson (Ibid.) have fashioned a toolkit to help decision-makers employ this framework in allocation exercises. The toolkit is comprised of five parts covered through 183 pages. The first part offers an introduction to the question of priority setting and expository material on basic economic concepts. The second part discusses different approaches to priority setting, including economic and non-economic models. Part 3 provides an overview of PBMA including examples and case studies describing how the process has been used in different contexts. Part 4 provides a discussion of the challenges to explicit priority-setting. And Part 5 provides a summary and concluding recommendations.

PBMA is not concerned with democratic legitimacy as a way of coming up with justified prioritization schemes. It is designed to maximize the use of the resources. (I will say more about this shortly.) What is interesting to note is that there is a growing interest in marrying PBMA and A4R (Gibson, Mitton, Martin, Donaldson, & Singer, 2006).[43]

### Analysis of Program Budgeting Marginal Analysis

*A) Understanding and Key Commitments:* Again, this cluster calls for leaders to acknowledge that decision-making is value laden, to develop a language for engaging value-questions productively, and to commit to testing reasons in a public sphere and democratize the decision-making in the organization.

Mitton & Donaldson (2003b) report that one of the virtues of the model is the space it creates for leaders to reflect on the patterns of allocation in the concerned areas. It affords a chance to take stock of where resources are currently being disbursed and the leaders' own personal values around patterns of allocation – irrespective of whether recommendations are actually followed or not. Moreover, they report that one of the advantages is the articulation of the decision criteria by which reallocation is actually recommended.

PBMA does not formally require testing reasons in the public sphere. Nor does it call for democratization of decision-making. The approach is based on utilitarian value commitments, but these are not recognized and articulated as such. The consequence is

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[43] A current research grant of Mitton's also created the opportunity to bring together Mitton, Gibson, and myself to compare approaches and future collaboration is being planned.

that while PBMA helps to recognize the evaluative nature of decisions in priority-setting, it only does so to some extent. Moreover, it does so as a means to maximizing effectiveness. But what it is aiming to be effective at – the broader, intrinsic values that the health system is aiming at is not directly acknowledged or addressed, and no support is provided for users of the framework to engage these deeper questions. Proponents recognize the challenges of value pluralism in society and indicate that the model leaves local stakeholders who participate in the advisory group to develop the criteria, but do not discuss how this is justified (Mitton, Donaldson, & Manderville, 2003).

As well, this approach is exclusively focused on the question of priority-setting and does not address broader types of system-level decisions. This necessarily limits its scope for making values explicit and living up to the value of publicity, richly understood. This is a major challenge for the approach that affects many of the recommendations below.

*B) Decision-Making:* This cluster calls for leaders to reflect on the way individuals and teams interact in the decision process, to explicitly think about Canadians' value commitments as they make decisions, and to actively make evaluative features of decisions widely transparent.

There is not much normative attention to the process of decision-making and the power dynamics of the PBMA process. While Mitton and colleagues identify how this plays out in their uses of the approach, they do not make principled arguments to defend any way leaders should work together.

*C) Decision Follow-Up:* This cluster calls for leaders to anticipate and support decision follow-up with education, communication, sustainability, downstream support, and evaluation and review plans.

In a research exercise aimed at evaluating the fairness of PBMA using A4R criteria, Gibson et al. (2006) identified the lack of communication and decision evaluation and review plans as key shortcomings of PBMA. PBMA also does not call for any planning to attend to the education of staff members required by reallocation decisions or to support those who might be impacted by the decisions in question. While sustainability was a value that regularly emerged in the development of criteria during the use of PBMA, formal sustainability planning is also not called for as part of the approach (Ibid.). This is reported as an area of improvement (Mitton, Patten, et al., 2003).

*D) Public Engagement & E) Staff Engagement:* These clusters call for leaders to develop short and long term philosophies and strategies of public and staff engagement. Specifically, this is to be done by supporting existing forums to be more deliberative, creating new deliberative processes, and ensuring those parties excluded from the process have meaningful access.

In terms of both public and staff engagement, PBMA relies almost exclusively on developing an advisory panel. Here, the importance of appropriate representation is to be balanced with manageability of the process. The goals of the process are maximizing outcomes and acceptability, not democratic legitimacy (Ruta, Mitton, Bate, & Donaldson, 2005). While it is suggested that along with senior managers, some clinicians should be involved on the panel, the participation of public members is optional. This limitation was also highlighted in applying the A4R framework to a PBMA exercise in a Canadian health region (Gibson et al, 2006).

The PBMA approach is blind to the crucial importance of meaningful public and staff engagement to justified system-level decision-making. This is not surprising of course as justification in the PBMA model is derived from economic principles and the economic value of efficiency. This orientation is at the heart of the limitation of the PBMA model. Again, it assumes the primacy of the utilitarian moral theory. But, as we saw in Chapter One, while this approach is certainly compelling there is no theoretical reason why it is more justified than other similarly compelling accounts of what is most important when it comes to allocating resources or making other system-level decisions. PBMA does not advance discussion about the democratic legitimacy of existing decision structures.

*F) Utility Criteria:* This calls for processes that are systematic, transparent, inclusive, context-sensitive, enable evidence evaluation, engage the user, provide practical direction, and that model good deliberation.

There are a number of features of PBMA that recommend it. For example, its proponents speak to the possibilities it creates for facilitating collaboration between physicians and administrators (Ruta et al., 2005). It does this by valuing equally the contributions of each when it comes to the development and use of criteria in the evaluation of different options. It also facilitates interdisciplinary education through the joint participation of these types of leaders in the decision process. The decision process is also directly geared to evaluating evidence in a systematic and organized way (Mitton & Donaldson, 2004b). This is facilitated by the use of business cases for evaluating different proposals for funding. This approach enables the standardization of evidence, minimizes the risk that the decision-processes are manipulated, and makes it easier to compare different options (Mitton, Patten, et al., 2004).

PBMA certainly represents an advance over black box decision-making that is the norm when it comes to health care resource allocation today. However, what is lacking is a systematic process for helping leaders to reflect on, articulate, and engage in discussion around what the appropriate decision criteria – or values – should be for reallocating resources. In addition to this, the PBMA is predicated on a conceptual framework that is itself insufficiently justified. The approach does not foster critical reflection on the goals of health system decision-making (even constrained to questions of resource allocation). Instead it is set up to favour those approaches that maximize marginal utility, with prescribed understandings of what utility is comprised of. Another challenge for the model is that while the process may lead to determinate decisions, these decisions need not actually be implemented. That is, the decision process is not necessarily linked to those with the authority to implement decisions (Mitton, Donaldson, & Manderville 2003). In a sense then, PBMA exercise can be seen as poor cousins of minipublics in that they are not empowered and are not explicitly tied to processes that are deliberative.

Mitton and Donaldson's toolkit (2004b) is instructive in that it provides one example of what a decision support resource might look like. In this model, heavy emphasis is placed on exposition of the conceptual framework that underpins the approach and broad gauge examples of the purposes that the approach has been used for by different groups of decision-makers trying to struggle with resource distribution challenges. The drawback of the toolkit is that it reads very much like a book and does not sufficiently engage the reader with interactive exercises where users can put the concepts of PBMA to the test. For example, the recommendations made in the summary are very general and do not articulate clear commitments that leaders will have to make in effort to advance the goal of justified decision-making:

> *Waiting for perfect evidence or the very best approach will serve neither today's nor tomorrow's purposes for priority setting. The key recommendation here is to get on with the task of setting priorities in an explicit manner, noting that transition costs may arise and mistakes will be made. It is well established that in competitive or entrepreneurial businesses, if you are not moving forward, you are in fact moving backward. To assist moving forward, it may that health organizations would find it useful to develop a 'priority setting team', which could be reassigned from current tasks, to carry out the processes outlined in this Toolkit.* (p. 173)

My concern with the above quote is not so much with the content. The recommendations seem reasonable and consistent with the approach provided in the Toolkit. The worry I have is with the format. The above is the second of three paragraphs of recommendations set out in dense text in the resource. I am skeptical about whether busy health care leaders will actually go through such text, and if they do, whether they will know exactly what their next steps should be.

### ***Lessons learned***

I suggest that PBMA and A4R set the bar for democratic legitimacy far too low. By only requiring that decisions and their rationale be available in narrow ways and to small groups of those affected, the approaches do not really live up to the value of publicity. And this comes at the expense of the legitimacy of the policies that ensue from their approach. A worry with my analysis is that my view is overly critical in light of the complexity of the regional healthcare context in Canada. A4R and PBMA both represent enormous gains in systematizing and making explicit the values at stake in priority-setting, given the constraints of the system. The rationale behind their more humble ambitions might be a strong sense of realism about the social fact of complexity. As any alternate approach including my own will face these constraints, it may be wise for me to be more charitable in my assessment. It is easy enough to say that decisions should be transparent, but in a context where union groups, the media, and a government that is very sensitive to upset in either of these camps, it takes courage to make rationales for decisions meaningfully clear and accessible. Nevertheless, I believe there is much more room to be ambitious here. If the degree of transparency I have argued for is indeed justified, then it is appropriate to name it as the goal and to begin to work with leaders to shape the context and begin taking steps to achieve this goal. The path may be arduous and slow, but a commitment to summit is much more likely to meet with success than a commitment to take just a few steps. A better approach will set the bar high.

Thus, I have three worries about both A4R and PBMA. First, they are primarily developed for priority setting and do not provide direction for system-level decisions more broadly. This limits their ability to impact the justification of system-level decisions broadly. Second the direction they provide remains at a very high level and does not give practical guidance with easy to use concepts and tools for decision-leaders. Third, and most important, they treat both staff and public engagement as one-off exercises, both undervaluing the normative importance of this requirement and remaining rather silent on how the output of this engagement ought to inform the decisions in question.

I have argued that meaningful decision support tools will have to follow the six clusters of operational recommendations I have provided. In helping to clear the path to developing such a resource, experiences with A4R and PBMA have highlighted pitfalls that will need to be avoided. I turn now to formally embarking on that path to actively developing tools to support leaders in Canada's regionalized health system to make better-justified decisions.

# CHAPTER SIX: TOWARDS A WORKBOOK FOR VALUES-BASED SYSTEM-LEVEL DECISION SUPPORT FOR USE IN CANADIAN HEALTH CARE

## Introduction

In Chapter One I determined that the appropriate source for the normative standards for system-level decisions in Canadian health care are derived from a participative understanding of democracy. I established the normative standards for justified decisions in Chapters Two and Three. In Chapter Four, I identified several operational recommendations for achieving the normative standards. In Chapter Five, I outlined some practical matters about decision-making as identified by leaders. I conclude the dissertation in this chapter, where my goal is to describe the process of developing a decision-support workbook for leaders working at the system-level in Canadian health care.

Cook and Oliver (2002) suggest there are five stages in the toolkit development process. The first stage involves identification of the theoretical framework that is to ground the toolkit. The second stage is the actual development and assembly of the toolkit. Third is the refinement stage, where end users test the toolkit. In the fourth stage, feedback from end users is incorporated into the resource. Finally, in the fifth stage, as the toolkit is used, examples of usage are captured as case studies that become shared resources included with the toolkit. In this chapter, I describe the creation of a decision-support instrument through these five phases. In the process, I refer to a decision support workbook I have developed (see Appendix B). The contents of this workbook are not a simple extrapolation from the earlier chapters of the dissertation; rather, many new ideas and claims are introduced in the narrative sections of the workbook, as well as much structure in the worksheets that floats free of the claims I defended in earlier chapters. It is important to note that the workbook is intended only as a useful example of the genre, thus allowing the very idea of a workbook to be tested in practice. Although the workbook itself needs to conform to the dictates of the previous chapters, it also includes much that is not dictated by theoretical or immanent values, simply by virtue of its complexity and detail. In other words, the previous chapters do not dictate every cell of every worksheet. These chapters place constraints upon the workbook and demonstrate its value, but an actual workbook will include detail that is based on contextual judgments made by those working in the field.

I begin in Stage 1 with a summary of the conceptual framework that undergirds the workbook. In Stage 2, I suggest what practically might go into such a workbook, cross-referencing it with the draft workbook currently in development and found in Appendix B. In this section I consider each of the recommendations and the decision criteria from the four clusters of operational considerations with a view to asking what might go into a support tool that would help leaders meet the recommendations and criteria, but in a manner that lives up to what leaders have indicated is important. Under Stage 3, I discuss the idea of testing the workbook with end-users. I describe both the protocol and the findings of a pilot study of the workbook conducted with leaders at the Fraser Health region in British Columbia. I discuss the consistency of the rationale for this testing with the normative standards developed in Chapters One through Three and suggest a proposed research design for additional testing of the instrument. In Stage 4, I describe amendments to the draft workbook that arose out of the findings of the pilot study. Finally, under Stage 5, I explore what the life of a workbook might be and what a "complete" workbook might mean in such a life. Here I also address the idea of the workbook as a living document, regularly updated and informed by case studies describing how the workbook has been utilized. The chapter will effectively constitute an overall proposal for what a decision support instrument for leaders making meso-level decisions in Canada's health system.

## Stage 1: The Conceptual Framework

The main body of this dissertation defends the line of reasoning that better system-level decisions should meet the following criteria:

- Those involved in making the decisions strive to demonstrate ideal communication in their deliberations where reason rather than power or other considerations determines the policy answer, and are clear and explicit regarding the values that are honoured and sacrificed in the decision and how the balance between these is justified.

- Decisions, the assumptions upon which they are made, their rationales, and the value trade-offs they imply are meaningfully transparent to the public.
- Decisions are made against the backdrop of a rich public sphere where deliberative dialogue is nurtured, including the democratization of decision-making in the system.
- They involve physician and staff engagement to an appropriate extent.
- They include education, communication, sustainability, downstream support, and decision review plans.

Additionally, for a workbook to be useful, it should

- Include processes that are systematic, transparent, and inclusive,
- Be sensitive to the context
- Have a clear role for evidence evaluation
- Facilitate the critical engagement of the user
- Provide practical direction about decision processes
- Be interactive and model for users what good engagement requires.

A decision-support resource, such as a workbook, should meet these practical criteria to enable leaders to live up to the normative standards. End users will engage a well-designed workbook that will lead to more ethically justified decisions.

## Stage 2: Key elements of a workbook

In this section, I provide a detailed description of what the directions given to leaders might look like, organized according to the six operational clusters identified earlier.

I suggested earlier that a limitation both Accountability for Reasonableness (A4R) and Program Budgeting Marginal Analysis (PBMA) share is that they are not designed or packaged in a way that allows leaders to pick up the material and, with some orientation, use it themselves. The drawback with this is that the uptake of the model will be limited to where there is external support for it. To enable broad usage of the framework, it is important that specific directions in a decision-support instrument, such as a workbook, be given to decision leaders in order to enable them to understand and carry out these recommendations by themselves in a manner that meets best practice standards in decision-making and team-building. But this raises a three-way tension between a) including a full set of sophisticated resources and tools that conform very closely to the normative framework I have articulated, b) providing a broad range of resources and tools that can be used in different contexts, and c) offering something that can be realistically used and cognitively absorbed by decision leaders. Sophisticated resources may best be used when accompanied by some form of expert support. For tools designed to be used without external support, the simpler approach may work best. In the workbook example in Appendix B, I have tried to provide a broad range of tools and resources for use in various contexts. I have attempted to make the tools as comprehensive as possible without needing expert support. Where there are both passive and active techniques that might be used for conveying ideas and helping leaders think through decisions, I have provided both. I have made these decisions in an effort to find that level of support that is comprehensive without being overwhelming. Where this balance is and how best to streamline the workbook will be determined through the development and testing stage of the process.

### *A) Understanding and key commitments*

The goal in this cluster is to help leaders take an intentional approach to their decision-making. Instead of being uncritically guided by whatever external forces happen to be strongest, the idea is that leaders should have a clear and justified understanding of how and for what reasons decisions in the public health care context should be made. Appreciating the evaluative nature of decision-making and learning to speak together about values and beliefs is in many ways is a journey of self-discovery for leaders. This can be a personal experience that may be best supported by active self-reflection and discussion with colleagues and mentors. Thinking about the role of the public in decision-making and how to effectively share power with them are sensitive and potentially psychologically painful areas of discussion. Whatever resources are provided here will have to be mindful of these sensitivities if they are to be effective.

#### Exposition of key ideas using relevant examples

Part of what is required is helping those whose actions are the focus of attention to understand the need for change. In the context of system-level decision-making in health care, this involves articulating the evaluative nature of decision-making and discussing the values that should guide the decision process. There are at least two ways of approaching providing support to facilitate understanding. One involves personal reading and reflection. I describe this here. The other involves active participation in decision-processes that demonstrate these key concepts. I describe this approach further below.

Writing a narrative about the lessons to be learned could help orient leaders to decision-making that lives up to the normative standards I have defended. The thinking here is that participants would read the ideas, ruminate on them, and adjust their perspectives to the extent that they found the ideas compelling. For example, a written section that deconstructs system-level decision-making in health care could be provided. It could illustrate that making value judgments is an inescapable aspect of policy work and help leaders recognize the evaluative nature of their work.[44] Expository sections on leadership in democratic contexts, democratic complexity, and the ways and means of making decisions public will also be necessary for assisting leaders to honour these recommendations. The use of examples in this expository process, similar to what is demonstrated in this dissertation, can clarify the concepts as well as how the process might be engaged in different ways.[45]

### Call for formal commitments

Part of the exposition of key ideas could be the call to formally commit to certain approaches. In light of the complex and fast-paced decision context of health care, meaningful public engagement will not simply happen. It will require formal, deliberate action on the part of health authorities. This can be done through the articulation of imperatives – commitments that leaders must undertake if they are to make defensible decisions at the system level.[46] For example, the expository sections on the evaluative

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[44] See pp.242–253 of Appendix B. The text tracks arguments offered in Chapters One and Two of this text.

[45] See pp. 235-241 of the Appendix B. Here, two main case studies are offered to frame the concepts in the workbook (both featured in this text): meso-level resource allocation and influenza pandemic planning.

[46] See Appendix B p. 254.

nature of policy and policy-making should lead directly to a formal request for organizational leaders to commit to making the value-laden dimensions of their work transparent.[47] As this would be the first of a number of commitments suggested, the workbook might include a section on the commitments required if leadership is to maintain the values that I have defended as being theoretically called for and argued as being immanent in the Canadian health care landscape. The commitment to publicity and to a long-term public engagement strategy should include assignment of formal responsibility for developing such a strategy accompanied by resources, financial and otherwise, to discharging it.[48]

If done well, this approach will support those leaders who like to read and who respond well to exercises of personal reflection and private study. A correlate drawback with the approach is that not all leaders will respond to this style of learning. Another drawback is that the approach to learning is passive. Leaders may accept the ideas at a theoretical level, but may only get a limited understanding of what is at stake.

## Formal decision process with accompanying worksheets and support materials

The second approach for helping shape a leader's understanding is by demonstrating the key ideas in an actual decision process. The terms *decision framework* and *decision process* have multiple meanings and can be confusing. When referring to a decision framework, I mean an overall decision philosophy that articulates the key steps in the decision process.[49] All decision-makers (that is, all people) have some process that we use to make decisions. We may create a list of pros and cons, consult people we trust for their advice, consider the short and long term implications of different options, and so forth. In my experience while leaders appreciate discussion of key concepts that is made practical, leaders respond particularly well to demonstrations of these concepts in the context of actual problem solving of difficult and real issues.

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[47] In the draft workbook this link is made from p.253 to p.254.

[48] See Appendix B p. 254

[49] See pp. 255 of the Appendix B. Here, the language of frameworks and processes is first clarified before a framework is presented.

I have been struggling for some time with what decision process best helps leaders understand the evaluative nature of their work. The process I recommend in the workbook has thus evolved over time. The process involves the following steps:

1. Identify key question (focusing the agenda)
2. Collect information (getting the facts straight)
3. Identify what's important (clarifying guiding values)
4. Prioritize what's important (putting the values in priority order)
5. Brainstorm alternatives (creative problem solving)
6. Judge each option according to values (systematic evaluation)
7. Make a decision
8. Live with it & learn from it (this includes reviewing the decision over time)

The idea is that a group of leaders can use this process on a live issue in one or two hours. I have used the process in a wide variety of contexts, from pandemic planning at the provincial level to the development of regional policy on drug testing for mothers suspected of substance abuse, to teams on acute care units trying to develop approaches for treating patients with complex family dynamics. I have found that it successfully helps leaders to separate their fact and value assumptions about an issue, to understand the importance of these distinctions, to recognize the evaluative nature about factual evidence they find relevant, and to critically reflect on the legitimacy of having their values guide decisions within a democratic context. What is especially powerful about the process is that it achieves the above while at the same time providing real direction for how to deal with a specific issue. The workbook could include such processes along with various related tools such as worksheets to help work through the various process steps.[50] Possible worksheets include means of identifying and evaluating factual

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[50] See Appendix B pp. 264-292. These worksheets reside in a template that can be modified and prepared for leaders according to each particular question. Of course, this requires someone to guide leaders through this work.

evidence, as well as ways of reflecting on and prioritizing value commitments. Such resources as meeting agendas may also be useful resources to include.[51]

## Support for an orientation to public engagement

Leaders will also need specific support for accepting a larger role for the public in decision-making, effectively giving up some of their power to rightly constituted public groups. They will need to be supported to know that there are practical ways to grapple with this very complicated area and there is assistance available as they move in this direction.

The interest in, research on and resources available for supporting public engagement in healthcare is growing significantly. Providing a summary of these sources and clear and simple ways to access them may help leaders accept this commitment to publicity and democratizing decision-making. It may help them to feel that neither is this completely new ground (though it may be for them), nor are they alone as they go on this journey. Providing leaders with cases where other leaders have taken risks and met with success may also be useful to help leaders feel a bit more comfortable with taking risks themselves.

## Policy on policy-making

This cluster calls for leaders to make commitments to decision processes that are transparent and have a central place for public engagement. A formal policy on policy-making is a very useful place for these commitments to be articulated.[52] Many organizations have policies on the function, content, and style of policies in their organization. The policy can establish the organization's philosophy of system-level

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[51] See Appendix B pp. 271. It will be useful for this agenda to be customized for the organizational context. Some groups might find the agenda too overwhelming, particularly if they are new to the framework and still becoming familiar with all the steps. However, as the group gains a better understanding of the process, this discomfort will abate and they will likely find it a helpful reminder of where they are in the overall framework.

[52] See Appendix B p.301-303. Many scoff at the idea of a policy on policy-making, seeing it as bureaucracy run amok. However, I suggest that an unwritten norm on how policy-making is to be done exists for every institutional culture. The device of a policy on policy-making can help articulate what is at stake and make this norm explicit.

decision-making, the process that policy-makers will follow, and the manner and extent to which it is expected the policy decision will be articulated. It is also a place where the procedures and protocols, including downstream support plans, can be described. The workbook could articulate what such a policy on policy-making might look like and offer direction on how to go about developing it in the organization.

### Glossary

Leaders are encouraged in this cluster to develop a shared language for discussing the values dimension of their work. A glossary may be useful for providing quick and ready access to the language of ethics and to the meaning of various substantive and process values.[53] Leaders might be encouraged to use this type of resource as a source from which to draw and build a shared understanding of the considerations that they find most important for guiding how decisions should be made in the organization.

## *B) Decision-making*

This cluster calls for leaders to consider the internal decision dynamics, the process value of transparency, and the substantive values of equity and efficiency. For this cluster as well, there are a number of different forms that support might take. These will include the more passive, academic sections of exposition of the values immanent in Canadian health care, the importance of considering these, and suggestions of vehicles for making decisions public. They will also include more active resources such as a decision framework, checklists for decision-making, and worksheets to assist with the articulation of decisions for public consumption and for choosing modes for public engagement.

### Exposition of key ideas

It will be important for the workbook to describe several key ideas including the role and importance of immanent values in any decision process, what each of these actually means, and what transparency requires and why it is important. In terms of team dynamics, a common, if unarticulated, misconception is that groups manage on their own

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[53] See Appendix B p. 305.

to figure out fair ways of relating to each other and making decisions when left to their own devices (Janis, 1982). However, as critical analysts of deliberative dialogue suggest, the way in which a meeting is structured has an important impact on how it is run. To this end, I suggest that a workbook should offer clear direction on issues such as how teams are expected to work together, what kinds of reasons will be accepted into the discussion, and how decisions will actually be made.

### Broad Decision framework with accompanying worksheets

In my approach, a broad decision framework demonstrates an overall philosophy of decision-making and includes stages that ensure that each of the important aspects of the series of steps through which decisions are made and implemented is appropriately highlighted. The broad decision framework I recommend for a workbook includes the following phases after a broad question or problem has been identified:

1. Clarify mandate, authority, and relationships amongst decision team (by team members)
2. Pre-meeting individual reflection (by individuals in private)
3. Team deliberation towards initial position (using a facilitated process such as described above on page 158 above)
4. Development of a consultation plan
5. Implementation of consultation plan
6. Team deliberation towards a final position (again using a facilitated process)
7. Development of a communication, education, evaluation, sustainability, and downstream support plan
8. Implementation of plan.

In this process exposing the values at stake in a decision to critical scrutiny must happen in at least three of the phases of the framework: when leaders reflect for themselves on the policy decision to be made;[54] when leaders convene to make a preliminary decision;[55] and when the final decision is made.[56] I have used this broader framework with leaders again on a range of issues, from various questions in influenza pandemic planning to the selection of structures for regional programs. In addition to the benefits of the decision process (which the framework involves using), the framework creates the space for personal reflection and reflection on decision team dynamics. It has also consistently allowed participants to come to an initial decision. The justification of the decision is easy to report, as the process itself requires clear articulation of facts and prioritized values. Here again, worksheets that explain and enable leaders to complete the various steps of a recommended framework will be useful.[57] Worksheets again could include draft agendas and timelines for the meetings that are required during different phases of the decision framework. Worksheets that assist leaders to articulate decisions and determine appropriate plans for making decisions public can also be useful.

### Checklist of questions to be considered

Healthcare providers are trained to handle complex criteria in their decision-making. To deal with this, a common form of tool is the checklist. The clusters of operational recommendations result in criteria for evaluating the justification of a system-level decision. A workbook might usefully capture these criteria, perhaps in something resembling a checklist. A workbook could suggest systematic methods for decisions to be evaluated against them.[58] This checklist would be used as a reference point through the decision process, and to evaluate a decision at the conclusion of the decision process.

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[54] See Appendix B pp. 265. Here, I have found it helpful to push leaders during their self-reflection to not only ask what is important to them with respect to the decision in question, but also why that is important, and going one layer deeper, why that is important. This helps surface the complexity and interrelationships of values, and also helps the leaders become clearer on what their deeper commitments actually are. In my experience, the first time that leaders are asked to do this, they find it a real struggle. However, after guiding them through such an exercise in a group setting, this starts to make sense and, like all the steps in this framework, becomes easier with the next iteration.

[55] See Appendix B pp. 271.

[56] See Appendix B pp. 282.

[57] These worksheets reside in a template that can be modified and prepared for leaders according to each particular question. Of course, this requires someone to guide leaders through this work.

[58] See Appendix B pp. 304. The culture of health care responds very favourably to such tools as checklists. The challenge here will be the comprehensive nature of this particular decision evaluation tool.

The criteria for evaluating the justification of specific system-level decisions in the checklist are reflected in the following questions:

- To what extent have the process values for the functioning of leadership teams charged with the responsibility of making the decision in question been made explicit, and to what extent have these values been meaningfully followed?
- Does the decision make explicit what decision is made, what values the decision is based on, what values are sacrificed, and how this balance is justified?
- Is the deliberative space where the decision is made inclusive such that no reasons are excluded from engagement and deliberative uptake of diverse perspectives is ensured?
- Is the deliberation recursive, in that both past decisions and the very framework for decision-making are open for review?
- Is the deliberation inclusive such that those affected by the decision could agree to continue to participate in the ongoing policy-making process?
- Do citizens have access to the process?
- If access is available, to what extent do citizens have the skills to engage in the discussion such that they are able to have their perspectives genuinely understood and responded to?
- If inequality exists, to what extent has the policy-making institution created forums for public consultation that overcome these existing inequalities?
- What efforts have been made to *support* existing sub-publics, working to empower them with that which is required to overcome existing inequalities?
- Did the professional expertise of the staff appropriately inform the decision process, and did the values of those staff affected by the decision, in particular those who must implement the decision, appropriately inform the decision process?
- Is there a communication plan in place?
- Is there an education plan in place?
- Are there sufficient supports in place for those who will be potentially compromised by the decision?
- Is there a sustainability plan for the decision in place?
- Is there an evaluation plan for the decision in place?
- By what mechanism will the decision consequences be re-assessed?

Many of these are of course questions that call for substantive answers and not simple tick marks. The idea in a sense is to package the complexity of decision-making in a form that speaks to leaders from a particular professional culture.

### C) Decision follow-up

This cluster calls for leaders to anticipate and support decision follow-up. It calls for:

- education plans to ensure that those who need training to implement decisions have this.
- communication plans to ensure that those that need to know about decisions are made aware of the relevant information.
- sustainability plans to ensure the long-term implementation of well-considered and justified decisions.
- downstream support plans to assist those who will be put in morally compromising situations as a result of the upstream decisions.
- evaluation and review plans to ensure that the actual consequences of a decision taken match those anticipated, and to take advantage of any changes in facts or values that may arise.

To my mind, the vehicles for supporting leaders to put these follow-up plans in place are key steps in both the decision process and the decision framework. A decision process could have questions and action items built in to facilitate practical thinking, planning and implementation of these follow up items.[59] It would be useful to bring formal attention to each of the strategies in this recommendation (education, communication review and revision, sustainability, downstream support, and decision process evaluation), in the broader decision framework.[60] And again, worksheets could be very valuable to help leaders reflect on and plan for each of the specific follow up areas.[61]

### D) Public engagement

Having committed to meeting a strong notion of publicity, this cluster calls for leaders to develop a philosophy of public engagement. This includes the identification and refashioning of existing forums where these might exist to make them more deliberative. It includes the creation of new deliberative processes within the public sphere and exploring areas where affected parties are not connected enough to have access to decision processes. And it requires actively seeking to overcome this. It also calls for

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[59] See Appendix B p. 261-2.
[60] See Appendix B p. 258.
[61] See Appendix B p. 290-292.

developing an interim public engagement approach for use until the broader public sphere is effective.

## Exposition of key ideas

To assist with this, a workbook might include a descriptive written section on the value of democratic legitimacy to allow leaders to understand the importance and relevance of public engagement. A regional strategy for public engagement needs to include at least the following three elements, each of which requires some explanation and articulation:

A. a region's understanding of and approach to public engagement,

B. a strategy of engagement with groups within the community – minipublics responding to the design questions, and

C. normative procedural standards for good deliberation.[62]

The normative procedural standards are also the criteria to be applied to specific decision- and policy-making processes to provide insight into the strengths and weaknesses of a given decision from the perspective of its coherence with the democratic value of publicity.

Practical direction for developing an ad hoc approach to public engagement, including the types of questions such a strategy would have to engage should also go in this section. The workbook would also benefit from a section that describes various models of public engagement and the strengths and weaknesses of these respective approaches. The number and quality of support resources in this area are increasing (Gauvin, Abelson, MacKinnon, & Watling, 2006, MacKinnon, Pitre, & Watling, 2007), and it would be useful for the workbook to at least reference these if not include some of the best examples in an appendix.

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[62] See Appendix B p. 295-300.

### Steps in the decision framework and process

For the recommendation regarding short-term public engagement, the decision framework should include consultation as an integral part.[63] The accompanying decision process could also highlight where and when consultation might happen within the decision process recommended.[64] In a number of cases where I have used the framework, the process has either stopped after the initial decision, or has skipped over the consultation stages. What is interesting is that this has usually happened in a sense against the will of decision teams. That is, teams using the framework become acutely aware of the limitations of their perspectives and of their own legitimate authority to make decisions. However, because of various resource constraints (such as time, understanding about how to engage the public, and resources to do so) decisions have to be made. In most of these cases, the articulation of the decisions reached have included explicit expression of the limitations of the perspectives included and the need for meaningful public and staff engagement for a final decision to be truly legitimate. And here once more, the formal process and framework could be accompanied by various worksheets, to help leaders identify where engagement might be appropriate, what types of engagement to consider, how to tie the outputs of these to the decisions at hand and so forth.[65]

### *E) Staff engagement*

Once again, this recommendation cluster calls on regional leadership to have in place a staff engagement philosophy and systematic strategies for facilitating staff engagement in the decision process. The areas suggested here are patterned against the steps for public engagement. Like the public engagement philosophy, I suggest an expository section that explains what is at stake in staff engagement and what good staff engagement entails would be useful. The broader decision framework should include a dimension that is dedicated to meaningful staff engagement. Ensuring that staff engagement is included, a

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[63] See Appendix B p. 256-257.
[64] See Appendix B p. 261-262.
[65] See Appendix B pp. 279-281.

formal step in the decision process or tree could help facilitate having leaders formally build this into their everyday decision-making. The call for a formal commitment to staff engagement, as reflected in the policy on policies, will likely be helpful to entrench this engagement in the organization's culture. Worksheets that help decision-makers consider what is appropriate involvement in particular decisions both in terms of the decision framework and process can again make it easier to engage the ideas in a hands on manner.

### *F) Utility criteria*

This cluster of recommendations calls for processes that are systematic and transparent, inclusive, sensitive to the context, and with a clear role for evidence evaluation; that facilitate the critical engagement of the user and not lead to decisions based on values embedded within the tool; that provide practical direction about decision processes and not be limited to theoretical reflection on these; and that are interactive and model for users what good engagement requires.

The call for systematic decision process can be met by the provision of the decision framework and the decision process. This is further assisted by support of the expository material about the importance of engaging the ethics dimension of issues in a systematic, organized manner. Transparency and inclusiveness imperatives can be captured by the commitments and actions dedicated to publicity under all of the clusters above.

Sensitivity to context will have to be demonstrated by using language that makes sense to intended audiences of users. This can be supported through the use of clear and numerous examples that illustrating both the concepts in the workbook and also how they should be used.

A formal role for evidence evaluation is required in this cluster. This is facilitated initially by helping the user understand and make the distinction between facts and values. This is further supported by steps in the decision tree and framework and by various worksheets. A worksheet that asks leaders to articulate in point form their understanding of the context of a situation, together with what evidence they are relying on for each of these points, and where others might disagree, can help the user see the assumptions they are making and achieve a deeper understanding of the quality of the assumptions.

Facilitating engagement by user, having them reflect on the issues at hand without giving them strong direction, for example about the values that should guide their decisions, can be accomplished in various ways. Creating understanding about the value and belief commitments required by any decision opens the door to this. Having a formal step in the decision framework for personal reflection on issues at hand creates the awareness and space required to engage materials. Providing worksheets that help the user to engage in reflective activity, both as individuals and as teams, can facilitate this as well.

Finally, ensuring that discussions lead to practical solutions and do not simply result in theoretical reflection can be achieved by keeping the focus of all of the worksheets and tools discussing values on the issues at hand and ensuring that realistic time frames are recommended for the various steps in the decision framework and tree. Making sure that the framework and tree call for solutions to be made and followed up on can also assist with this.

My hypothesis is that a workbook that incorporates these elements will be perceived to be useful by decision leaders and will lead to decisions that honour the normative criteria for justified decisions. This hypothesis will require testing. Initial work and reflections on research design are described in the remaining sections of this chapter.

### Stage 3: Testing With End-Users

Whatever instruments are developed to meet these norms, maintaining the norms of public and staff engagement through deliberative dialogue requires that both those who use the book and those affected by its outcomes be involved in testing the tool's worth and offering critical feedback that is based on deliberative ideals. This feedback then needs to inform the workbook.

Although conducting a comprehensive research program for the proposed workbook is beyond the scope of my dissertation research project, in this section I suggest what a comprehensive qualitative research project on the use of this instrument might involve. Before doing so, I describe a pilot study conducted with the workbook, as this pilot offered insights into what a comprehensive qualitative study should include.

### Research questions

For the comprehensive qualitative research project evaluating the use of the workbook, the principal question is whether the workbook actually helps leaders make decisions that meet the criteria articulated in the four operational clusters. Alternatively, it is important to determine how the resistance of leaders to making ethically justified decisions shifts with the use of the workbook.

The first goal of the pilot study was to engage senior leaders working in Canada's regionalized health system, with a view to receiving some initial feedback on the language and structure of the workbook. A second goal was to identify real concerns and benefits of the contents of the workbook. Also, I needed to determine if the pilot was an appropriate method for testing the workbook, thereby gaining insight into the research design for a comprehensive qualitative research project.

The following specific research questions helped focus the inquiry in the pilot study:

- Does the language and structure of the workbook make sense to the research participants?
- Do participants have any real concerns with the content or ideas of the workbook?
- What do participants believe are the benefits of the content or ideas in the workbook?
- Do the participants believe that decision leaders might actually use such a workbook, and what would enhance the likelihood of its use?
- If used, do the participants believe the workbook will actually help leaders meet the criteria of ethical justification?

## Methods

### Validity and Rigour

It was recognized that this pilot test would only be able to confirm face and content validity of the workbook and research design. The research questions and design thus involved familiarizing research participants with the workbook and asking them to use the concepts therein, and then exploring their experience to determine if the basic ideas and structure made sense (relevance) and were easy to use (utility). The transferability of the findings from this pilot will be limited by the relationship between the method used and the understanding sought, and by the degree to which the method is executed rigorously.

### Research Ethics

Because the pilot study was being conducted under the aegis of two institutions, research ethics approval was obtained from both the Health Research Ethics Board at the University of Alberta and the Fraser Health Research Ethics Board.

### Participant Selection

The purpose of the pilot study was to gain insight into the perspective of senior leaders within the health system regarding the workbook. It was from this pool that participants would be drawn. My hope was to engage four to six participants in a focus group discussion of the above questions. Because the workbook is aimed at leaders throughout a health region and across the continuum of care, it was valuable to have diverse representation in the participant group across urban and rural areas, across the continuum of care (including areas of acute care, long-term care, and home care), and across professional backgrounds (business administration, healthcare administration, medicine, and nursing). Patton (1990) nicely articulates the rationale for this approach of maximum variation sampling, stating,

> *It aims at capturing and describing the central themes or principal outcomes that cut across a great deal of participant or program variation. For small samples, a great deal of heterogeneity can be a problem because individual cases are so*

> *different from each other. The maximum variation sampling strategy turns that apparent weakness into strength by applying the following logic: Any common patterns that emerge from great variation are of particular interest and value in capturing the core experiences and central, shared aspects or impacts of a program* (Ibid. p. 172).

The following specific criteria were used in the selection of participants:

- The individual should be a senior leader in their organization, who has some authority and influence over way in which at least some system-level decisions are made.
- The leader need not work in a particular geographic context, and may come from an urban or rural setting.
- The leader need not be responsible for any particular area within the continuum of care, and may lead in a primary, acute, home, or long-term care setting.
- The leader need not have a particular professional background, but should currently occupy or have recently occupied an administrative role in a regionalized health care organization in Canada.
- The leader should be able to relate to the case study used to test the tool in the pilot project.
- The collection of participants should be as diverse as possible relative to the above criteria.
- The leader should not have been exposed to the particular decision frameworks and processes presented in the workbook (to minimize bias).

In addition to the criteria above, the participants were chosen because the researcher knew them, and, in the researcher's estimation of their reputation, they would be willing to fulfill the requirements of participation.

Since the pilot study was to be completed in a relatively short time period (four to six weeks from beginning to completion), the research subjects were drawn from Fraser Health. Serving southern B.C., this is one of Canada's largest (by geographic size and population) and fastest growing (by population) health regions. The size of the pool of senior leadership in this region was roughly 200 people. Of these, approximately half would not meet the bias criterion, having worked with or been supported by the researcher in his role as ethicist for the region.

It was anticipated that, due to the nature of their work, some participants would be called away at the last minute and be unable to attend their scheduled focus group.

Accordingly, eight participants from this pool of candidates who met the criteria above were selected to participate to meet the hope of having between four and six research subjects. If all could participate at the same time, then one focus group would be scheduled. If not, then two focus groups would be arranged, each comprised of four participants. It quickly became apparent that one meeting would not be logistically possible, and so the latter plan of two focus groups was implemented.

To choose the participants, a list of eight potential participants who maximized the diversity of the group was created. From this list, two declined the invitation to participate due to scheduling conflicts. Both, however, indicated they would have been willing to participate had their calendars permitted, and expressed appreciation at having been asked, as well as a keen interest in the work. Two new names were added to the list, and all agreed to participate. It is speculated that some of the reasons why these individuals agreed to participate included a general interest in the area of ethics, the novelty of this approach, a growing awareness of ethics services in the region, and a search for tools to assist with challenging situations in their professional lives.

Of the eight who agreed to participate, three were forced to cancel at the last minute and five were able to complete the research steps in the pilot, spread out over two focus groups. There was significant diversity among these five. Each had over 15 years of work experience in the health system. Two were men and three were women. Two of the participants were physicians with key administrative responsibilities (Medical Directors). One Medical Director works at a specific institution – a tertiary care hospital. The other is responsible for a region-wide acute care program. The other three participants were Senior Directors. One plays a leadership role in the regional communications office. One oversees region-wide end-of-life care programs, including hospice and palliative care, as well as spiritual care. The third serves another tertiary acute care hospital in the region.

In terms of distribution, three participants attended one focus group, while the other two attended the second scheduled meeting. The Medical Directors and Senior Directors were spread between these two meetings, so that both meetings included at least one physician leader and one administrative leader. The focus group of two included the institution-based Medical Director and the regional end-of-life care Senior Director. The focus group of three included the Medical Director of the regional program, the Senior Director from communications, and the Senior Director from the other acute care institution.

### ***Focus Group Protocol***

Feedback received during the two focus groups was the source of data collection. The focus group protocol consisted of a description of the context of the meeting, the primary questions to be used to elicit feedback, and secondary questions to engage others to confirm or disagree with the initial respondent's answers. The following questions made up the focus group discussion guide and provided the framework for the second hour of discussion:

Introductory question:

- Will use of the workbook assist you and other leaders at Fraser Health to make better, more ethically justified decisions?

Key questions:

- What made sense to you in the workbook?
- Was the wording useful?
- What are your big questions that the concepts and tools failed to clarify?
- What could be done to make the workbook easier to understand?
- What could be done to make the workbook easier to use?

Ending question:

- What are the most important changes that you envision the workbook influencing?

### ***Research steps and data collection: What actually happened***

The research protocol included the following steps:

1. A list of potential research participants was developed, based on the above criteria.

2. Potential participants were contacted by telephone to discuss the research project, their interest, and their availability to participate, until eight participants had been confirmed.

3. Consent forms, a copy of the workbook, and the pre-work instructions were sent to each research participant.

4. Administrative assistants for the researcher and the research subjects collaborated to schedule focus groups, with a view to having four participants in each focus group.

5. An email was sent to the participants, asking for questions about the consent form and confirming what was involved in the research project.

6. Prior to the focus group, each participant independently took approximately two hours to review the workbook and engage the pre-work forms in the case study.

7. Three participants and the researcher attended the first focus group. At each focus group meeting:
    - Refreshments were provided.
    - The researcher began by inviting introductions and explaining the two-fold purpose of the focus group session: in the first hour, the decision process in the workbook would be used to move towards a decision in the sample case; the second hour would be used to gather participants' feedback on the language, structure, and content of the workbook.
    - The signed consent forms were collected. All participants in both focus groups came prepared with their consent forms and had no questions about these.
    - For the first half of the focus group, approximately one hour, the researcher facilitated a discussion of the case study according to the worksheets in the pre-work document.
    - For the second half of the focus group, approximately one hour, the researcher listened to the participants' feedback on the workbook, according to the questions identified above.
    - The second hour of the discussion was recorded on a digital voice recorder, and the researcher took handwritten notes of the participants' feedback.
    - The researcher then explained that the next steps in the research would be to analyze the data and revise the workbook. He thanked the participants for their time and contribution, and indicated that a summary of the findings would be shared with them, along with the revised version of the workbook.

8. After the focus group was completed, the voice recorder was sent to a professional for transcription. This individual listened to the recording, and captured expressions in both text and punctuation using word processing

software. The transcription for the first focus group spanned 18 pages of double-spaced text.

9. Once the transcription was complete and the file was sent to the researcher, the researcher listened to the recording, comparing it against the transcribed notes to confirm correspondence with his understanding of utterances, pauses in conversation, assignment of utterances to speakers, and so forth.
10. The researcher then compared the transcription to his handwritten notes to search for inconsistencies.
11. The second focus group was then held. Two participants and the researcher attended the meeting.
12. The process of transcription and confirmation was repeated. Transcription for the second focus group spanned 25 pages of double-spaced text.

Both transcriptions were analyzed through an iterative process of review, coding, and theme identification, as described below.

## ***Data Analysis***

In large part, the six steps identified by Bernard (1999) guided my approach to data analysis:

- obtaining interview transcripts,
- identifying themes,
- comparing themes,
- identifying relationships between themes,
- building theoretical models and checking them against negative cases, and
- reporting using direct quotes from the transcripts. (p. 443-444)

Data analysis began immediately following each of the focus groups, as I reviewed my handwritten notes repeatedly (ocular scan method (Ibid. p.445)), and began to see various patterns emerge (intraocular percussion method (Ibid.)). Once the audio files were transcribed, I compared these with my handwritten notes, and discovered that the handwritten notes were, partly transcriptions of the participants' comments and partly my own immediate analysis of these comments. At this point, I focused on the actual transcriptions of the focus groups, and referred to my handwritten notes only to check my analysis of the transcripts.

Despite having predetermined categories implicit in the questions guiding the focus groups (e.g. was the wording useful?), I began the analysis with an exploratory/inductive approach, using an open coding method (Ibid. p. 444). Here, I used the techniques of in vivo coding (Ibid.), where I simply sat with the transcripts, highlighting the sections. Then, I began to annotate my reflections on the textual data. Consistent with Russell's description (Ibid.), I made three types of notes: code notes, describing the concepts being discovered; theory notes, summarizing how I thought the concepts fit together; and operational notes, about how I would or should organize my analysis.

At this point, I began developing a codebook of the notations I was using to assign occurrences of certain phrases to different themes. I reviewed the transcript for each focus group several times, refining the codes I was assigning to text and the codebook each time.

I pondered over a number of interesting decision points in my journey of analysis. For example:

- What would count as an occurrence worth noting?
- If the same participant repeated the same comment three times within the focus group, should this count as three occurrences? Was this repetition a function of the personal importance of the point being made or because he or she felt that, I, as the facilitator, was not hearing what he or she was saying?
- How many occurrences were required for a comment before I would consider it a theme? If the meaning of a comment could feed more than one theme, should it be counted in both, or only one?
- How specific should the code map be?
- Should contrary statements on the same theme have their own code or be reported as part of the same code, but as a contrary point?

To enhance the validity of the analysis of the feedback received in the focus groups, I have left a trail of both the questions encountered and my responses to these decisions. The following is the final codebook that emerged through the analysis.

| First-Order Theme | Second-Order Category | Third-Order Category | Fourth-Order Category | Code |
|---|---|---|---|---|
| Language/ Text | Novelty | New material – new language | | 1.1.1 |
| | | Not new material | | 1.1.2 |
| | Writing style | Accessible | | 1.2.1 |
| | | Not accessible | | 1.2.2 |
| | Readability | Easy to read | | 1.3.1 |
| | | Took time to read/hard to read | | 1.3.2 |
| | | Overwhelming | | 1.3.3 |
| | | Technical/academic | | 1.3.4 |
| | | Abstract | | 1.3.5 |
| | | Good use of examples | | 1.3.6 |
| | Interest | Interesting | | 1.4.1 |
| | | Boring | | 1.4.2 |
| | Repetition | Appropriate because necessary | | 1.5.1 |
| | | Unnecessarily repetitious | | 1.5.2 |

| First-Order Theme | Second-Order Category | Third-Order Category | Fourth-Order Category | Code |
|---|---|---|---|---|
| Concepts | Clarity of concepts | Clear | | 2.1.1 |
| | | Could be more clear | | 2.1.2 |
| | | Areas of confusion… | | 2.1.3 |
| | Relationship between concepts | Linked | | 2.2.1 |
| | | Links between these areas unclear… | | 2.2.2 |
| | Assistance with comprehension of concepts | What helps comprehension | More Examples/case studies | 2.3.1.1 |
| | | | Tools | 2.3.1.2 |
| | | | Other | 2.3.1.3 |
| | | | Use one example all the way through… | 2.3.1.4 |
| | | What limits comprehension | | 2.3.2 |
| | Level of Detail | Insufficient detail | | 2.4.1 |
| | | Appropriate detail | | 2.4.2 |
| | | Too much detail | | 2.4.3 |
| | Valuable | Overall approach valuable | | 2.5.1 |
| | | Clarifying the key question | | 2.5.2 |
| | | Public consultation | | 2.5.3 |

| First-Order Theme | Second-Order Category | Third-Order Category | Fourth-Order Category | Code |
|---|---|---|---|---|
| Tools & Framework | Practicality | Practical | | 3.1.1 |
| | | Not practical | | 3.1.2 |
| | Utility | Useful on its own | | 3.2.1 |
| | | Useful, but can enhance | | 3.2.2 |
| | | Areas needing improvement | | 3.2.3 |
| | | What could improve utility | | 3.2.4 |
| | | What is not useful | | 3.2.5 |
| | | Not clear how to apply immediately (without doing | | 3.2.6 |

| | | | | |
|---|---|---|---|---|
| | | background reading) | | |

| First-Order Theme | Second-Order Category | Third-Order Category | Fourth-Order Category | Code |
|---|---|---|---|---|
| Layout | Purpose | Purpose clear | | 4.1.1 |
| | | Purpose not clear | | 4.1.2 |
| | Audience | Audience clear | | 4.2.1 |
| | | Audience not clear | | 4.2.2 |
| | Organization | Well organized | | 4.3.1 |
| | | Areas where organization confusing | | 4.3.2 |
| | | Tips for improving organization | Tabs/Headings | 4.3.3.1 |
| | | | Numbering | 4.3.3.2 |
| | | | Other | 4.3.3.3 |
| | | Things to avoid | | 4.3.4 |
| | Length | Appropriate length | | 4.4.1 |
| | | Too long, make shorter | | 4.4.2 |
| | Look and Feel | What would improve | Visual Aids | 4.5.1 |
| | | | Directions for immediate use | 4.5.2 |
| | | | Go online | 4.5.3 |
| | | | Clearer "how to use this guide" section" | 4.5.4 |
| | | | Other | 4.5.5 |

| First-Order Theme | Second-Order Category | Third-Order Category | Fourth-Order Category | Code |
|---|---|---|---|---|
| Application | How this should be applied at Fraser Health | What will be required for application | | 6.1.1 |
| | | Clarify rollout plan | | |
| | | Get corporate commitment to formally adopt | | 6.1.2 |
| | | Prepare folks for key issues (with examples) | | 6.1.3 |
| | | Incorporate into new physician/staff orientation | | 6.1.4 |
| | | Make adoption of philosophy required, with attendance at workshop | | |
| | How this should be applied for general audience | Culture change | | 6.2.1 |
| | | | | 6.3.1 |

| First-Order Theme | Second-Order Category | Third-Order Category | Fourth-Order Category | Code |
|---|---|---|---|---|
| General/ Overall | Contribution | Use of workbook will make a positive contribution | | 7.1.1 |
| | | Use of amended workbook will make a contribution | | 7.1.2 |
| | | Expected benefits | | 7.1.3 |
| | Current context | Appetite | | 7.2.1 |
| | | Challenges | | 7.2.2 |

| | | | | |
|---|---|---|---|---|
| | | Opportunities | | 7.2.3 |
| | Pilot Study | Biased participants | | 7.3.1 |
| | | Directions not clear | | 7.3.2 |

Table 1. Codebook for qualitative pilot study

Once these themes emerged, I began writing a discussion of findings. During this process, the analysis continued, as relationships between themes continued to emerge, and I began searching for negative cases to disconfirm apparent themes.

## Limitations

While there is some controversy about the minimum number of participants required for a focus group, particularly for a pilot or feasibility study such as this, the small numbers of participants is a limitation of the findings. In particular, the meeting with only two research participants may resemble a semi-structured interview more than a focus group. To some extent, this was mitigated by the diversity of participants and the rigour of the focus group protocol.

Although checked against delivery, there was still room for human error in the transcription process. Words may have been misheard or misunderstood. Feedback from one participant may have been mis-assigned to another. In addition, errors in punctuation may have led to misinterpretation of the ideas on which participants placed emphasis.

Given that the researcher and the research participants are leaders in the same institution with working relationships and commitment to mutual support, clear bias was introduced into the study. This was alleviated by the fact that no meaningful conflicts of interest existed between the researcher and the research subjects (except the desire on both parts to help the other succeed), and both share roughly the same level of power in the organizational hierarchy.

## Discussion of Findings

The themes that emerged from the data analysis were divided into the following six main areas: language and text, concepts, framework and tools, format and layout, and application and general feedback.

## Language and text

The two main themes in the feedback received were that the material and language introduced in the workbook were new, and that the workbook took time to complete.

> *As I was reading it I thought, 'Well, this is, you know, it's really interesting. It's brand new information. It's a new language.*

All participants consistently reported that this way of thinking about issues and decisions was new. This was a little surprising given that the participants came from different professional backgrounds, worked in different parts of the system, and had varying histories within the organization. With this diversity, one would have assumed this way of thinking might have been familiar to at least one of the participants. On the other hand, the number of participants was few, and none had any formal training in philosophy.

I take two lessons from this theme. First, in the introductory sections, it will be important to acknowledge that readers may find this to be a new way of thinking. Second, rather than assume a shared background understanding about decision-making, I will have to very clearly articulate and explain the concepts on which the workbook is based.

> *I think it's really technical. There's term that – wording that put together that I might not have put words together like that. So then I have to think about what that means, some sentences. When I say I read it twice, I probably read it ten times in some of the sections because I try to make sense out of what's the meaning of it because it's – every page I find that when I read the next page I need the first page understanding.... So if you ask me, 'Is it easy – is that easy?' It's not easy to read.*

Implicit in this quote is the fact that the participants took their task in the research project seriously, as they seem to have genuinely struggled with the material. The extent to which the ideas in the workbook build on each other also became apparent, as did the consequence when these links were not explicit. When they were not described well, or were described with inconsistent language, the participants became confused and lost. This is consistent with, and exacerbated by, the report that this was seen as a new language to them. This finding underscores the importance of using accessible language to describe the concepts, clarifying the links between the concepts and the tools that build on them, and ensuring that terminology is defined and used consistently.

## Concepts

Three themes emerged in this area:

- the value of the concepts, in particular, clarification of the key question when dealing with a policy issue and the guidance around public engagement;
- a lack of clarity between some of the concepts and the decision framework and tools; and
- the value of using examples to illustrate the concepts, with a strong call to use more examples.

*Importance of Concepts.*

> *I think there's an amazing amount of information that was so valuable that I think it should be used. And that we empower the people who are doing the work by almost having this – the framework and the decision process put in place.*
>
> *When the first available bed policy came out, we had to say, 'Well, how are we going to do first available bed for people who are dying?' I mean, this is a pretty emotional issue about telling people they have to leave hospital and they have to go to a hospice. And there was lots of emotion and feeling around that. So we had about three meetings, bringing huge numbers of people together. We did get to an outcome. And – but I was thinking if I'd have had this process it really would have been better because I was just kind of fumbling.*

All of the participants found the concepts useful. Once they were able to grasp the ideas, the concepts seemed to help them clarify their thinking on issues and understand how to identify and productively struggle with differences in perspective between team members. I was not entirely surprised to find this as in my experience many leaders despair over the lack of systematic support and direction when making difficult decisions. In offering a map (where none previously was identified and used), this approach provides hope. An interesting question is whether participants found the concepts valuable because they provided *a* systematic way of thinking, or whether there was something especially useful about *this* particular systematic way of thinking. The comments below do suggest the participants found elements of this approach useful, but it would be prudent to study how participants evaluate this approach relative to other decision-support instruments.

> *You have to realize in your study your chosen subjects are biased… not only that you create interest for us which is – you create the bias. But we are biased because we are the ones that are interested.*

Another possible confounding factor in this finding, as identified by one research participant, is that the research subjects had some relationship with me, the researcher. This may have led to biases around participants' personal support for the researcher, their desire for the success of the researcher's professional activity in the region (ethics services), and/or the participants' previous exposure, directly or indirectly, to the researcher's values as demonstrated in his approach to providing ethics support to the organization. Notwithstanding these possible biases, participants agreed that the concepts in the workbook are valuable. This reinforces the importance of moving forward with such tools in general and with this workbook in particular.

> *A: It's really a process because it does clarify a lot of things, though, doesn't it?*
>
> *B: Um-hum.*
>
> *C: You know, I think oftentimes we're so focused on finding solutions to the…*
>
> *B: To the wrong question.*
>
> *A: If we can just discipline ourselves to come up – to think clearly and come up with the right question, we might just move the process along more quickly.*

The participants in one focus group particularly emphasized both the difficulty and benefit of the idea of identifying the key question when struggling with a system-level decision. This step in the process often seems to take an inordinate amount of time and can be tedious. It would not have been surprising to find busy, solution-driven leaders frustrated by this step; however, the participants neither demonstrated nor reported feeling this way. They were meaningfully engaged in the question, and saw the importance of ensuring they were operating together in resolving the issue. This finding validates this key idea and step in the decision process.

> *In terms of the consultation plan, I don't know whether there's any way that you could give an example... If I'm really honest about this, so often around public consultations someone like me would tend to think, well, you know, it's got to be 10,000 people and you have to have six meetings... What are some small steps that we could take around public consultation that wouldn't sort of have to be the whole enchilada... And what groups already exist out there so that you could go to and that would be the tools to go... But who could I invite and how could we do that. So I think some specifics in there about, you know, there's consultation and then there's, you know, widespread, I mean, the – what you have to do for a pandemic exercise would be a little different than to say, Okay, after we made those decisions about who would get the hospice beds, are there some public groups we could– small groups that we could have gone out to see did the decisions we made, make sense to you guys.*

In terms of the idea of engagement with both physicians and staff and the public, participants reported deep support for the importance of this idea, and were convinced that this should be a key element in any approach to making good decisions. However, they indicated a lack of understanding of what the purpose of consultation should be and how such initiatives are operationalized.

> *I think typically in many health authorities there's almost more like put your head down and hope nobody complains about what you're doing.*
>
> *So there's almost the sense, even at the ministry level when we go there and you try to bring in other groups that would have a say on the decisions you're making, they don't want it.*

Participants also expressed frustration and cynicism about the possibility of meaningful public engagement. They felt it would not be possible to undertake any such engagement without organizational support, and this support would not be forthcoming, in part because those organizational leaders were understood to be accountable to the provincial government – they have no interest in supporting meaningful engagement.

I take three important lessons from this. First, it validates the importance of engagement and its inclusion in the approach defended here. Second, it suggests that the workbook should treat this section with special care at both the conceptual and practical levels. Conceptually, it will be important to be clear about why engagement is important, and thereby, what the objectives of engagement should be. This should be linked to practical direction about the kinds of engagement that might meet these objectives and include very concrete examples. Third, this finding validates the call made earlier in the dissertation for the development of an organizational policy where the philosophical orientation and commitment to public engagement is articulated. This call may indeed be extended to higher levels of public bodies, such as ministries of health and provincial governments.

Participant comments on public engagement also raise the question: Does the tool place too much responsibility on individual decision-makers and decision-making teams to engage in consultation? As I argued earlier, in my view, for the decisions made at the system-level in Canada to be legitimate, they need to be made against and informed by deliberations in a vibrant public sphere around the system. This requires systemic changes that may be preconditions for locally meeting some of the goals the dissertation articulates for the healthcare manager's work. The call in the dissertation is not to engage in one-off moments of engagement, but for the organization to develop a philosophical approach and comprehensive strategy for public engagement. Thus, the main call for improving the legitimacy of decisions is for senior leaders to work with their colleagues and superiors to build this public sphere.

Certainly one implication for the workbook and processes it encourages is that all leaders, from local managers to the CEO, will need *strategies* for bringing consultation into their work and bringing superiors onside with this project. I would argue that the degree of responsibility both for advocating for the development of the public sphere and for directly including forums of participation into the decision process is proportional to the relative place a given leader occupies in the institutional hierarchy. A senior vice-president has more responsibility to create a public engagement infrastructure around the organization and to tie individual decisions to ad hoc engagement forums than does a colleague at the director level. And the director's responsibilities are greater than the manager's. The workbook should make this clear.

*Lack of clarity between concepts and tools.*

> *So I read the first part and I looked – I really studied the four dimension of the system. So I study it, I thought that, hum, this is sort of stepwise, tell me how to*

> *make, you know, decision, formulate question and it give me some definition of it. So I said, Okay, that's good. And then when I go to part two then it becomes six phases...I had complete confusion on that. And then I have to go – that's why I read the third time on this is because why does that correlate with that?*

As this quote suggests, at times it was unclear how the concepts presented in the theoretical part of the workbook correlated with the steps in the overall decision framework or in the more detailed decision process. There were also instances where different descriptors were used to indicate the same idea, but these equivalences were not made plain. For example, the terms "strategic values" and "instrumental values" are used interchangeably, but only the latter is explained.

> *A: For instance, there's a lot of terminology here... when I read 'instrumental value' and then you put 'strategic value'... When I read it and then I said instrumental value... okay, that one is strategic value now.*
>
> *B: Yeah, there's two meanings. Instrumental or strategic.*

These criticisms are very well placed and indicate opportunities for major revision of the workbook. Participants identified earlier that discussion of concepts such as values and beliefs represented a new language. One can easily see how using related terms such as considerations, instrumental values, intrinsic values, strategic values and so forth without defining the terms or how they are related could create real difficulty. The feedback provides an opportunity to revise the workbook to ensure that terms are defined well. It also offers the chance to associate the elements in the exposition section of the workbook explicitly with the various practical decision tools.

*The need for examples.*

> *Yeah, I, too, really support the idea of an example because if you have, let's say, six or ten very different scenarios and you kind of work through the process in a variety of different scenarios, some where it's just a small decision that has to be made and in other circumstances, like, a pandemic, for instance, where some really tough, tough decisions need to be made. I think having a series of examples is really good.*

The examples in the workbook were seen as very valuable, and the passage above clearly expresses the call for many more examples. This was the most resounding theme in the pilot study, reinforced repeatedly in the conversations in both focus groups. It was suggested that more case studies be used to illustrate the concepts and show how the tools should be used. Examples should speak to the various contexts and professional backgrounds of the individuals who will to use the workbook.

## Framework and Tools

Participants offered two main themes in their feedback. First, although the tools were seen as useful, a number of strategies were suggested to improve their utility. Second, participants were unsure how to move directly to using the tools without first having to complete the background reading.

### *How to improve utility of the tools.*

> *So other than the workbook, I need a consolidation session which is what will help me.*
>
> ~
>
> *I don't know if there's any way you can reduce those phases or you say... depending on how the decisions that– I mean, some decisions would be much more confined and local versus corporate decisions. And they have– the amount of detail in each phase would be a bit different and how do you say, like, certain corporate decisions like let's imagine we were going to decide about all 70 year olds, anyone over 70 doesn't get admitted to hospitals anymore in Fraser Health. Well, clearly that would have to be a huge thing. But figuring out about who goes into the hospice beds, much smaller.*

Various ideas for improving the usefulness of the tools were provided. Participants reported that reviewing the tools with the researcher in the first half of the focus group meeting was very useful, and indicated that this type of tutorial session, where they could engage in the material with support, would significantly increase their ability to use the instruments. This suggests that a formal in-service of one or two days to assist leaders to understand and practice using the proposed tools may be a valuable addition to the workbook. It was also pointed out that because people learn in different ways, the material should be presented in different formats.

> *The exercise that you shared with us today and the tools, Bashir, that you shared without a partner when they were going through that ethical situation, was really fast, crisp, enabled us to really hone in on what needs to be done.*

~

> *A: Going through the process that we went through today, Bashir, really helped because it just really zoned in on what's important. So now, if I were to re-read the book, going through it again, I could connect what's in the book with what we've just gone through.*
>
> *B: But I think the whole point here is that, you know, people learn and retain things in different ways so–*
>
> *A: Some people are spatial learners; others are audio learners and so forth. So that's why B's idea of having the tutorial and so forth and to provide this as a learning package in a variety of ways or whatever works for people they can take that approach.*

There were also calls for what I term an *accordion* approach to the process. That is, the decision tree was seen as very comprehensive (and appropriately so) for very significant decisions. However, the participants felt it would be useful to include some sort of guide that would help users gauge to what extent the decision they were facing required utilization of the process to achieve a justified decision. I repeat an earlier quote to pick up on this point:

> *I just don't know if you could reduce, you know, if there were phases I don't know if there's any way you can reduce those phases or you say – I don't know if there's a way of kind of cutting the various levels to say depending on how the decisions that– I mean, some decisions would be much more confined and local versus corporate decisions. And they have– the amount of detail in each phase would be a bit different and how do you say, like, certain corporate decisions like let's imagine we were going to decide about all 70 year olds, anyone over 70 doesn't get admitted to hospitals anymore in Fraser Health. Well, clearly that would have to be a huge thing. But figuring out about who goes into the hospice beds, much smaller.*

~

> *A: I guess there isn't a real process for determining what type of issues have the most merit in going through a comprehensive decision-making process such as this. I mean, we certainly can't do it on every issue that you're faced with every day. So I guess you just use your best judgment there 'cause there's no way to -*
>
> *B: Target the people who use these things all the time.*
>
> *A: Right.*

This is very interesting feedback because it touches on one of the most challenging aspects of providing support to decision-makers. It illuminates the struggle between making decisions quickly and without complication, and taking the appropriate time and energy required to make decisions systematically and well. The feedback suggests that the workbook could be improved by including direction on what kinds of decisions require using the comprehensive decision framework. I had hoped that the workbook would be a self-sufficient resource for leaders. The feedback suggests that as it stands, it cannot stand by itself. I will have to determine whether there are other ways of providing the initial tutorial that participants found so useful. Perhaps this could be delivered through an online resource (discussed below). However, if this support cannot be provided online then the workbook will fall prey to the same criticism I leveled at the alternative approaches I considered (A4R and PBMA). The worry is that the reach of the tool will be very limited. At this stage the workbook may have to be simplified significantly to be accessible to leaders.

*Quick application.*

> *I'm afraid you're going to lose them. Because I think part two you want it to be able to stand-alone. And I think it could with case studies in it so that if I'm a director and I've got this group who's going to meet, you know, in two weeks, could I go right to part two and I think there'd be enough self-learning in there that I could do that. But I'm afraid if I had to go all the way through part one, I won't get there.*
>
> ~
>
> *As you mentioned there's lots of great background here but practically, if I was looking to use it as a tool I'd need, I felt it was too much time to go through all that to get to the action part.*

An important theme that emerged is that the workbook should provide a quick-use type of direction for those who have to make decisions promptly and lack the time to go through the detailed expository sections. Participants worried that readers might become bogged down in the expository sections and never progress to the tools. Moreover, facilitating the quick use of the tools and demonstrating their effectiveness might increase the buy-in of users and compel them to study the expository sections more carefully. Conversely, participants expressed the importance of understanding the expository sections before using the tools. Failure to do so would result in overlooking various dimensions of the tools, leading to poorly-justified or inappropriate decisions.

> *A: Well, I doubt if you'd be able to do the action part without clients having an understanding of the whole concept.*
>
> *B: Yeah, so that's the challenge, right.*
>
> *A: But I would think what you wouldn't want to do is to unleash people who are not – who don't have a basic understanding of the processes that you're trying to teach us onto all sorts of people. So, you know, I think the book is great but it needs some structure.*
>
> *B: Yeah, I agree. And not as, say, 'Now I've read the workbook, oh, I think I'm an expert in ethics. I'll go out and use the framework for all my decisions. And I'll be completely justified in how we make them.' Yeah, that is a risk.*

There are two possible harms of direct use of the tools without attending to the preliminary processes:

- Without sufficient understanding of the relative importance and justification of each step, users may simply fail to follow the step to the extent required, and
- If not undertaken well, this approach may lead to a false sense of satisfaction about the quality of their decisions, thinking that their decisions must be sound because they have used an ethics-based process.

The question here is whether the workbook is too long and intricate, or whether it is of appropriate length and detail. In the event the former is true, the workbook will require serious revisions to make it more simple and brief. If the latter, the practical implications may include reversing parts one and two of the workbook, and offering direction for immediate use on a decision near the beginning. In this case the harms might be minimized by explicitly outlining them as part of the limitations of proceeding directly to the instruments. As with the discussion about length following soon, the most important criterion for determining this seems to be the perspective of users. That is, if users find the complexity and length of the resource prohibits them from usefully engaging with the material – reading it and going through the process steps that are required – and if my goal is a resource that is useful, then the workbook is too long and complex. Initial indications obviously suggest that this is the case, and so I will have to immediately work at improving the workbook from this perspective. The revision will then need to be retested to see if the appropriate balance has been reached.

## Format and Layout

Participants provided feedback under two main themes. Their comments suggested the value of greater clarity about the purpose of the document and what users should be able to accomplish after having used it and they offered tips to improve the overall organization of the material.

### *Purpose and deliverables.*

> *How is to be used and who is to use it and when is it to be used? I don't know what your thinking was in terms of how you're planning to roll this out... would you just give it to anybody or will there be time to, like, in a certain group of people that would be more inclined to – would need something like this more so than others?*

Participants reported a sense of ambiguity about the audience of the workbook – whether it was to be targeted exclusively to leaders at Fraser Health or more broadly. The ambiguity did not arise when they used the instruments, but surfaced as they began thinking about how to improve the workbook for broader application. Clarity of audience was deemed important because this would influence how the workbook should be presented for meaningful uptake. Because it is hoped that this resource will be widely consumed, the lesson here may be to simply state whom the workbook is for and what it offers to the user in the opening pages.

### *Improving organization.*

> *The other way that a person can actually get through a lot of information is using the headings and subheadings as a way of telling a story as well. So that the key nuggets of thought and the concepts that you wish to convey, you almost have a story going at the heading level. So even if they – their eyes – if they cast their eyes just to the headings, they will in a sense be getting a very, very high level version of the story or the point that you wish to make. And then they go in a little bit deeper when they– it's almost like the links on a website. You get deeper and deeper as you go into the text.*

~

> *The other suggestion I'd offer from a format or graphic design or layout perspective is that it would be easier to get to the material if there was more bullets and lists used. Periodically in the text there's– you will have, like, '1, 2, 3'or 'a, b, c.' and it kind of runs together as a text. And if you pulled that out and just ran it as bullets or listed it, it's much easier and quicker to get through the information.*

A number of practical suggestions were given for improving the organization of the workbook, including the use of tabs, section headings and so forth. The advice described in the above quote was an obvious and simple illustration of the need to improve the organization of the workbook, and will be implemented.

## Improving overall appeal and utility

Under this theme, four sub-themes emerged: the need for visual aides, a parallel online resource, length, directions for immediate use, and miscellaneous ideas for improvement.

*Visual aids.*

> *Some people are spatial learners, others are audio learners and so forth. So that's why [participant name]'s idea of having the tutorial and so forth and to provide this as a learning package in a variety of ways or whatever works for people they can take that approach.*
>
> ~
>
> *If you change those diagrammatically in boxes or using, you know, we're used to that. And that would be really – maybe put some colour in there, you know, spend some money.*
>
> ~
>
> *And the other issues maybe put it – the whole – in an algorithm form. So people could look at a page and see the process. Like, I mean, at the beginning where they're – whenever you go through the process here but just at the beginning to say, 'These are the steps,' like an outline.*
>
> ~
>
> *Is there such a thing as a visible model you could show me? Because I guess if I think, well, to me, the word "decision framework" is usually something that flows out of a model. So if the model for ethical decision-making had five hooks on it and then you worked out your processes from there, that would probably help me see. And so what I would – the framework is like kind of the, you know, the*

> *cupboard and the various pieces in the cupboard that you hang your clothes on. And so if you show me that, that might be helpful to people.*

The need for other ways of representing the material was an important theme that came out in both focus groups. Because of the corresponding nature of the concepts and the relationship between the concepts, the decision framework, and the decision process or tree, these would lend themselves well to pictorial illustration. It was pointed out that those leaders who come from clinical backgrounds are used to seeing flow charts and decision diagrams, and converting the ideas to these formats would make a significant contribution to their uptake.

This reminds me of the shift from the oral reading of philosophical papers to the use of multi-media, PowerPoint presentations to convey information – demanding to meet the values of both effectiveness and aesthetic enjoyment. The practical upshot of this feedback is the need to improve the overall aesthetic appeal of the workbook, and to use visual representations of ideas and the linkages between main ideas wherever possible.

*Parallel online resource.*

> *A: And if this was online, what you could do is, if that little framework could– or your little box explodes into something else, right. Like you could double click and there's the questions behind them, right.*
>
> *B: It would be so good if you can put it online – I can see that – that would be a lot more understanding.*
>
> ~
>
> *A: You might actually consider having some type of web-based learning platform where it leads you through a practical example using the tools. Because this is extremely useful to go through this with yourself and I think it would be fairly easy to set up something like this on a web-based platform where people could walk through and go, 'Oh, right, okay. This is what I filled out for what I thought the facts were and here's what the tool is telling me their interpretation of the facts are. That helps me understand what's meant by facts on this.' That type of thing, you know.*
>
> *B: A tutorial.*

*A: A little tutorial, yeah.*

~

*Other than the workbook, I need a consolidation session which is what will help me. It's sort of like I think what we've been trying to think about the online education has been we're going to get the sort of a bit of a theory and the ideas out and then you come to something. And you've done that homework before you get there. It saves significant time. And people know kind of what they're coming to.*

In the focus groups, there was a resounding call for a parallel online resource to accompany the physical workbook. One idea for the online support range was to simply post the workbook online, but in a way that immediately linked to related concepts, tools, and examples, regardless of whether one was looking at a conceptual section, the overall decision framework, the detailed decision process, or an example. Other ideas included online tutorials to help users understand how to apply the instruments, brief video presentations explaining the ideas, and the provision of examples. An exciting idea that was suggested, which will be discussed in section five below, is allowing users to share their iterations of the tools. This would both increase the number of examples available and create a repository of past decisions as a guide for future decision-making – an approach consistent with the casuistic approach to conventional bioethics – something Daniels advocated earlier.

*Length.*

*I would suggest that it hopefully will be thinner.*

The need for a less dense version of the workbook came out from the focus groups. However, it was not clear whether this was because there was unnecessary information, the sheer size was daunting, the volume of information was overwhelming, or it took too long to absorb. This could have been explored more extensively. As per the discussion above, efforts will have to be made to make the resource more concise.

*Miscellaneous ideas for improvement.*

The participants offered numerous ideas for improving the overall format and layout.

Layout of examples:

> *You know what I would like, this is fairly – this is part two, you lay out all your stages of framing the questions that is that this page is what they actually need to get the old question. And then on the opposite page, actually, there's a concrete example*

Glossary addition:

> *I really liked your use of the glossary at the end. But I was missing a definition of about– so much of what you talk about is based on beliefs and values and they're not defined in the glossary.*

Adaptation of context of individual "micro" situations:

> *I wondered if you could take some pieces that are on a more micro level and just – because presumably people would be able to apply this to problems in – within the hospital or allocated resources in the operating room or the ICU or critical, things like that. It might be those sort of examples might be useful.*

Sign-posting time requirements:

> *Knowing how long this will take at the outset, I knew I had to put that amount of time aside. And because the information, a lot of it and the language is new, it would have been very difficult for me to go back to it, like, to spend 15 minutes and then go away from it and then come back and try and get into it again. So that was important information to know.*

Strategic repetition:

> *A lot of what those other books do, that – the books [inaudible] publish a lot of these sorts of self-help books, they repeat things over and over and over again, right. They– and they make a point, they give an example and then they'll come back to it again and again [inaudible] nauseating so– pounding it out. And yet that's– people retain those things. So there must be some reason for how that's done.*

Summarizing key messages:

> *In his leadership book, he does exactly that, you know. He'll go through this chapter and then at the end of the chapter, he blocks off in a square and using bullet points, he'll pick something like, you know, key messages to remember or things to remember, the top ten in that chapter or the top five. And he just bullets out the message, you know, 'bah, bah, bah, bah." And then just goes through the top seven or ten or five points. But he blocks it off in a box so it's very separate. And a person can– sometimes I'll go back to his books and I'll just go back to the summary because it gives me that– pulls out the essence of what he was trying to say which I think is a very effective.*

Clearer references:

> *When you go to this page on page two, how to use this guide, I don't know if you encountered it, when I first read, like, according for the– in the last paragraph it say it is recommended to go straight to section – in part two entitled decision process…I couldn't find it for the longest time.*

Place the application first:

> *I wonder practically if you almost could switch the part one and two. Like, could your part two stand alone and if someone wants the theory behind it, they could go to that.*

Follow-through with an example:

> *I think workbooks on some of these, again, if you were following an example through, if you actually filled out those worksheets and showed us what it looks like, that would have really helped.*

Use tabs:

> *If each of the phases were sort of tabbed that would probably help, right.*

The next iteration of the workbook should explore these ideas, to determine which are consistent with the broader feedback received and the normative requirements of the framework, and then implement these changes.

## Application and General Feedback

Under this heading, discussion and reflection in the focus groups crystallized into two themes: the current appetite for such an approach; and ideas for how to facilitate the uptake and practical application of the approach.

*Appetite for the approach.*

> *I hear more and more, maybe it's the field that I'm in, like, palliative, end-of-life care but I mean, more and more I'm hearing staff – now some of it is because of the work that you've done about heightening people's awareness. But very much wanting to work ethics into the work we do but realizing, like, we only have so much time to do that. And that they need more knowledge and understanding.*

It seems quite clear that there exists an appetite for this type of material. Not only did this come through in the focus groups, it regularly comes through in my own professional work, and is evidenced by the growth in the number of organizations developing ethics resources and hiring professional ethics staff. This suggests that the proposed work is timely, and that the workbook needs to be developed in time to take advantage of the window of opportunity that is currently open to this kind of thinking.

*Practical application.*

> *I also think there's a lot of power in the use of common language. So if there is that particular framework that's supported by the organization that has the potential to create that power around the use of common language.*
>
> ~
>
> *I also like the idea if the organization is endorsing this type of decision-making framework for leaders of having accessibility to workshops as they do with many of the other leadership programs.*
>
> ~
>
> *There are certain programs, learning programs, in – the organization is sharing with the leaders and other people in the organization. I'm wondering if this should not almost be one of those 'must attend' type of, like, turn this into a course or workshop and make it a must attend type of– so that we would be able to– building that common language and asking questions*
>
> ~
>
> *I think this should be– if you have a simple version that can include an orientation package.*

Reinforcing the importance of these ideas and instruments, participants indicated that the materials should become part of the everyday understanding of how decisions ought to be made within organizational culture, and in particular, the culture at Fraser Health. As the quotes indicate, ideas included ensuring it is part of physician and staff orientation, making it a required course for leaders, and institutionalizing the decision process through expectations of leaders for ethically justified decision-making.

Of course, the decision to take such actions will be in the hands of institutional and organizational leaders. However, the articulation in the workbook of some of the ideas presented by the participants for how this approach might be normalized may assist with making this kind of approach part of the fabric of day-to-day decision processes for leaders.

## Stage 4: Outcomes of the Pilot Study

### *Summary of recommendations*

Despite the limitations of the generalized findings of this pilot study, this exercise in qualitative research has been exceptionally useful, both in highlighting what the target audience finds useful and needs in their research tools, and in helping to reshape the draft workbook itself. The following is a summary of the recommendations drawn from the analysis of participant feedback in the pilot study:

- Acknowledge that this may be a new way of thinking for the reader.
- Do not assume there is a shared background understanding about decision-making.
- Clearly articulate and explain the concepts on which the workbook is based.
- Ensure the language used to describe the concepts is accessible.
- Make the correlations between the concepts and the tools clear, and use visuals wherever possible.
- Ensure that terminology is defined and used consistently throughout the workbook.
- Proceed with such tools in general, and with this workbook in particular, taking advantage of the window of opportunity that is currently open to this kind of thinking.
- Treat the section on consultation with special care at both the conceptual and practical levels. Conceptually, be clear about the importance and objectives of engagement, and link this to practical direction, including very concrete examples on types of engagement.

- Call for the development of an organizational policy where the philosophical orientation and commitment to public engagement is articulated. This call may indeed be extended to higher levels of public bodies, such as ministries of health and provincial governments.
- Use more case studies to illustrate the concepts and show how the tools should be used. Examples should speak to the various contexts and professional backgrounds of end users.
- Reverse parts one and two of the workbook.
- Offer direction for immediate use on a decision early in the workbook.
- Identify concerns with proceeding directly to the instruments and bypassing the preliminary processes.
- Articulate clearly who the workbook is for and what it offers to the user.
- Use headings and subheadings as a way of highlighting the crucial details of the workbook.
- Improve the overall aesthetic appeal of the workbook
- Develop a parallel online resource to accompany the physical workbook, linking related concepts, tools and examples.
- Develop online tutorials to help users understand how to apply the instruments.
- Develop brief online video presentations explaining the ideas and providing examples.
- Allow users to share their usage of the tools.
- Make the resource *appear* thin and accessible.
- In the workbook, offer ideas for how this approach might be normalized.
- Engage further study of the workbook use, including how participants evaluate this approach relative to other decision support instruments.

I use the tools in the workbook on a regular basis. The next steps in my journey with the workbook include taking all of these recommendations into account and redrafting the workbook accordingly. The still preliminary plans for the workbook are that once it reaches a level of completion, it will be published as an online resource for decision leaders at Fraser Health. Fraser Health Ethics Services may also undertake further qualitative testing of the workbook with a broader audience. The Provincial Health Ethics Network of Alberta has expressed interest in publishing the workbook to make the tools available to a wider audience.

### *Toward a research design for a comprehensive study*

Consistent with the argument offered earlier, confidence in recommending the workbook to end users will, in part, be derived from evidence that it actually does enhance the ethical justification of decisions made by leaders in health. In other words, as the goal of the research is to have direct impact on practice, and as the research makes an empirical claim about the impact of the workbook on decisions that leaders make, it will be necessary to assess whether this claim is actually true. To this end, a comprehensive research project exploring this evidence will be an important next step on this journey. While such a research project is beyond this dissertation, I offer a few reflections on important dimensions of such a study in the remainder of this section.

#### *Methods*

Qualitative case study methods should feature prominently in a proposed research design for comprehensive testing of such a workbook. As a method that focuses on development and understanding of meaning, the exercise of qualitative research actually supports the normative goals of the project: more thoughtful, systematic reflection by decision-makers on the values that should guide system-level decisions. Qualitative research methods often involve immersion of the researcher into the context of a situation where communities or small groups of people are engaged in specific questions. By using methods that allow the participants to share stories through which their values and beliefs surface, themes about key issues emerge. While not intentionally models of democratic deliberation, the philosophy and impact of these methods can and have had significant impact on how these decisions are made, and probably should be seen as models of deliberation.

#### *Validity and Rigour*

To improve the confidence about the reliability of the interpretations (triangulation) in the larger study, the results from the focus groups should be confirmed through other sources. As participants' insights into the use of the workbook deepen, this knowledge should inform the design of probing questions in subsequent focus groups. In addition, the validity of the analysis of the findings should be confirmed through extensive member checking and peer debriefing.

### ***Participants***

A comprehensive testing of the workbook will require careful reflection on the broader research question, and will not be limited to exploring the perspectives of health system leaders. In particular, because a basic premise of the project is that ethically justified decisions involve meaningful public and staff engagement, participation from these groups will need to be included in the evaluation of the concepts, frameworks, and processes included in the workbook. Those whose consultation is required by the normative foundations of the workbook (staff and public) will need to be involved in a way that allows them to grasp how leaders use the workbook and reflect on whether this engagement is meaningful. The research design will need to be sensitive to this purpose of involvement, and find creative ways of facilitating this.

### ***Generalizability***

The workbook can be used in a number of different ways, and is expected to have an impact on immediate decisions and on the broader decision-making of the users. To obtain a reasonable sense of the utility of this workbook, it may be valuable to explore these various dimensions. For example, it may be useful to compare the experience of users making decisions guided by the workbook solely with users guided by the workbook and a facilitator. As well, it may be prudent to explore the longitudinal impact on the user, suggesting a research design over a longer time. It may be useful to examine the utility of this type of resource in comparison to some of the other approaches examined earlier, such as PBMA and Accountability for Reasonableness.

### ***Data Analysis***

The pilot study has provided some categories that may be useful in future analysis of participants' engagement with the workbook itself (language and text, concepts, framework and tools, format and layout, and application and general feedback). These may provide starting points in future data analysis for a small part of the broader research program.

### Stage 5: Continual updating for a shared resource

A fascinating stage in Cook and Oliver's (2002) roadmap involves capturing examples of the usage of the toolkit as case studies, and sharing these as resources included with the toolkit. If it can be incorporated in a practical way, this idea shines for a number of reasons. First, it resonates with the call for more examples to illustrate the concepts and how the tools might be used. Indeed, there is good reason to ascertain it does so in a more enhanced way than using a crafted case example of a fictional case or even a real case tailored to illustrate key points, because it would portray how participants actually engage with the resource. Second, over time, it would lead to the creation of a bank of decisions and their rationale, thus becoming a key vehicle for the intellectual history of the organization. This would allow future leaders to see not only what issues have been dealt with historically, but also the rationale considered in making the decisions. Third, it would allow the researcher and others involved in providing support to leaders to assess how the tools are used and how they might be improved.

One key challenge with capturing and sharing examples of how the workbook has been used is confidentiality. Many of the issues that might be seen as subject matter for the use of the workbook will be sensitive questions that organizations see as internal and may not wish to publicize. There may be practical strategies around this, such as creating web spaces on an organization's intranet, which limit access to the cases to those working within the system. Notwithstanding such strategies, there is an important relationship between this concern about confidentiality and the normative requirement that good decisions involve meaningful engagement. The transparency required in sound decisions may suggest that worries about confidentiality are, in fact, not justified.

The second challenge with sharing examples of how the workbook has been used will be to provide users with easy means of recording their experiences. Assistance with this may be derived from the worksheets provided in the workbook itself. For example, a template might be created where the group's deliberations on an issue is captured in worksheets for each of the dimensions of the decision framework provided in the workbook. These worksheets could be what become shared, along with a brief narrative of the group's experience with the workbook.

In summary, the idea of facilitating ongoing sharing of experiences of engagement with resources such as the workbook advances the normative goals of the values-based approach to system-level decision-making that is defended in this dissertation. It also resonates with users' calls for more illustrations of the concepts and tools in the workbook. In addition, it provides those involved with supporting leaders the opportunities to determine how these leaders are using the resource, which can provide valuable information about how to improve the workbook over time.

# CHAPTER SEVEN: CONCLUSION

## Recapping the journey

Canadian health authorities face challenging system-level questions as they try to fulfill their mandates of meeting the health needs of populations they serve. Leaders face a broad range of issues that include questions about setting priorities, system-organization and integration, and clinical service. I have taken up two research questions in this dissertation. In the first part, I sought to determine what makes a system-level decision in this kind of healthcare context ethically justified. In the second, I explored how leaders working in this setting can be supported in practice to make better decisions according to the normative standards identified.

To answer the normative question I turned to concepts in ethics. I considered dominant approaches from moral theory as sources for justification. These approaches evaluate decisions by how well they conform to chosen substantive principles or values. I found that these approaches did not provide a method for deciding between their diverse foundations and recommendations, especially in the context of a pluralist society. I thus turned to a process-centred approach grounded in deliberative democratic theory. If it is consistent with the values of Canadians, then this approach allows the negotiation of difference by delegating responsibility for resolving the disagreement to public deliberation. But its legitimacy depends on whether Canadians accept the moral authority for making these choices, or whether they favour delegating this authority elsewhere.

This led me to a review of the values embedded within Canada's healthcare system. Here I found that there was good reason to think that Canadians do favour a participatory democracy in this context. It is important to them to be meaningfully involved in system-level decision-making in health care. I also found that certain other value commitments of Canadians emerge. Substantively, it is generally important to Canadians that health care be equitably distributed based on need and that we have access to effective healthcare resources. Procedurally, it is important that leaders are held to account for their decisions as part of good governance and that the expertise and integrity of healthcare professionals be respected.

Based on these normative findings, I defended five clusters of recommendations to leaders for making decisions consistent with deliberative norms.

A. Self-understanding and commitments: Leadership should appreciate the evaluative nature of decision-making and commit to transparency and democratization within the system.

B. Decision-making process: Leadership should attend to internal decision dynamics, directly consider substantive values immanent in Canadian health care, and make decisions and justifications public.

C. Decision follow-up: Leadership should ensure decisions are appropriately supported with education, communication, sustainability, downstream support, and evaluation and review plans.

D. Public sphere: Leadership should develop and implement a comprehensive public engagement approach.

E. Staff engagement: Leadership should develop and implement a comprehensive staff engagement strategy.

Living up to these recommendations would yield decisions that are justified. Members of the community would have reason to accept these decisions and the state would have reason to compel acceptance if necessary. I recognized at the outset, however, that simply coming to such a normative conclusion would not make much difference. This change will require significant courage and political action from leadership. So I turned to the practical worry, how might leaders be supported to follow such challenging recommendations?

For this I consulted literatures on decision-makers' perspectives and the content and design of training materials. Leaders demonstrate a keen interest in tools and resources that would help them with the difficult questions they face. But they suggest that the tools need to be clear, easy to use, and sensitive to the complexity of the context in which they will be used. Training materials that are interactive and enable the user to think for themselves about the problem to be solved were described as useful and consistent with the normative directions identified. Based on this, I offered a sixth cluster of recommendations:

F. Utility criteria: Decision support instruments should include processes that are systematic and transparent, inclusive, sensitive to context, have a clear role for evidence evaluation, facilitate critical engagement of the user, provide practical direction about decision processes, and model what good engagement requires.

I also recommended a values-based system-level decision workbook as a resource for leaders. The literature suggested a series of stages for developing useful tools. I had developed the theoretical model for the tool earlier in the dissertation. I then followed a step by step process to determine what should go into a workbook if it is to align with the normative recommendations. I then undertook qualitative testing of a workbook prototype and reported on a pilot study conducted with leaders at the Fraser Health region in British Columbia to test the prototype's context and content validity. Finally, I reflected on what should guide comprehensive qualitative testing of such an instrument.

## Contributions and limitations

This research project bridges the worlds of theory and practice and advances current thinking in political theory, bioethics, and health policy. It also provides resources to improve decisions made in practice.

At the theoretical level, the research contributes to current debates about democratic legitimacy. At one end, it extends deliberative democratic theory to the regional health policy arena. It demonstrates how in this specific context decision-making could be adjusted to better live up to democratic norms by identifying the extent to which system-level decisions are value based and ensuring that the values that guide these decisions arise from meaningful public engagement. At the other end, this application casts new light on the theory itself. It provides support to the position within deliberative democratic theory that popular sovereignty is possible in contemporary, plural, complex society. It develops further the roles of the public and leaders in the system, and how deliberations in these two arenas might be connected. The research advances discussion in bioethics by articulating what commitments to organizational ethics require if they are to live up to the values of deliberative democracy. And it supports a move away from the traditional principlist approach to clinical ethics, to a more broadly accessible model featuring discussion about beliefs and values. The research contributes to literature in health policy by setting out standards of justification for health policy and articulating recommendations that makers of health policy need to live up to if they are to meet these standards.

Practically, I hope that the output of a relevant, user-friendly instrument for use by members of regional boards and senior management will help to clarify the nature of the ethical dimension of meso-level healthcare policy-making, and will provide practical guidance on how to maximize the democratic legitimacy of allocation decisions. Use of this instrument will directly assist policy-makers facing difficult decisions, and also affects all those impacted by these decisions – society at large – by leading to more succinct, better justified and well-considered policy, and to greater confidence in the policy-making process.

One limitation of the approach concerns the choice of a workbook as the practical vehicle to help leaders achieve the normative standards of democratic legitimacy. For the ideal that I have described to be realized, it will take enormous political change at local, regional, provincial, and perhaps even national levels. Assuming they see the need to do so and are committed to making this happen, for regional leaders to be able to facilitate the emergence of a public sphere around health care, they will have to engage with and secure the support of two types of partners. They will of course have to engage with the civil society – the public – in various ways. But health care is neither independent of other public goods, nor does it tidily fit within a given jurisdiction. For example, regions will need the political and resource support of provincial governments to make this happen. The provincial government and other health regions will have to decide to align their own decision approaches or defend less inclusive models. Engaging the public will require the mobilization of local communities. Another important link to facilitate this will be municipal governments. And as an educated public is required for deliberation to be meaningful, health system leaders at all levels will have to commit to making their own decisions and decision-processes transparent. A key element in all of this is the willingness to share power. Leaders in political office and in health care will have to be comfortable ceding some authority for decision-making (Fooks & Lewis, 2002, Maddalena, 2006, Abelson et al., 2002).

Any workbook can only take the user so far on this journey. As participants in the research study indicated, even at the level of a health region, the culture shift I am advocating will require significant facilitation. Methods of mandated education workshops, orientation programs, would be necessary to make this happen. But these would of course not be sufficient. As indicated above, dramatic changes to managerial cultures, legal and political regimes, and managerial hierarchies, will be required. I am hopeful about the prospects of moving system-level decision-making at the regional level in Canadian health care. However there are a number of areas where this optimism is dampened. Specifically, these concern the partners with whom the regional leaders I am targeting must work. Regional health organizations are themselves part of the much broader and more complex health system. They relate with and are impacted significantly by provincial and federal governments and professional unions and organizations. I believe that regional leaders acting alone can make significant change within their subsystems. However, on their own they will not be able to facilitate broader change at the provincial or national levels. And the prospects for change require either independence or support from their political masters – provincial leaders. If this freedom or support is not forthcoming, that is, if provincial leaders are not concerned with or actively do not accept the arguments I offer and do not seek justified decisions, then the task of the regional leader is made significantly more difficult, if not impossible.

## Future Direction

This research provides the theoretical reasons for paying attention to the process by which system-level decisions are made in health care. It then uses a workbook to articulate these reasons to busy health system leaders and to demonstrate their relevance in the context of the real issues that such leaders face. From this point, the work of this project needs to proceed at many levels.

At the level of the decision-maker facing challenging questions in the current climate, we need to discover whether the workbook can actually help leaders with their work and whether use of the workbook leads to better decisions. In both cases the goal will be to determine how to improve the workbook to better achieve its goals, assuming that it can do so. This research is likely best undertaken through the ongoing partnerships between researchers involved with providing ethics support and regional leaders. It could be done through a series of qualitative case studies where the workbook is used with leaders as they work through concrete cases.

Also at this level, it will be useful to collaborate with other researchers involved in similar work to explore the complementarities of these approaches. (Future research is currently being planned, for example, with the proponents of Accountability for Reasonableness at the University of Toronto and the Program Budgeting Marginal Analysis at the University of British Columbia.) Where there is meaningful difference between these models, it will be useful to test which approaches are best suited to supporting what types of problems. This might be done by working with similarly situated teams, having each go through an exercise of resolving a priority setting exercise using one of the three models, and then qualitatively evaluating both the outcomes of the decisions and the respective experiences of the participants using the same measurement standards.

It will also be important to collaborate in future research with colleagues in the area of healthcare organizational change management to explore how culture shifts happen and how they are best supported. Working together may allow a broadly shared values-based language for leadership support to emerge. It will hopefully also ensure that the latest understanding of effective tools for change is incorporated into ethics-based decision support resources such as the workbook.

At the level of regional public engagement, it will be important to help demonstrate on a small scale how new and existing public forums might be held and linked to very specific and narrow system-level decisions. For example, ethics services for a health region might work with regional public health departments that are already inclined towards greater public involvement, and choose specific, pending, system-level decisions for which public engagement can be carefully planned and implemented according to the workbook's decision framework. Such a project could benefit from first reviewing experience in other government-run systems that are taking up deliberative methods, such as the environmental sector. It would also benefit from a review of the literature on the lessons emerging about how best to embed deliberation. The support for leaders thinking about public engagement could be developed significantly further in the workbook. The lessons from research in this area could also be used to bolster these workbook tools.

At the level of the regional board, it will be useful to work with board members to help understand how they see their accountability relationship with the public and how this relationship might be improved. Interested boards could be taken through a process of orientation to public engagement. Here they could be exposed to the various understandings of public accountability and different methods for engaging the public at various levels through a region. A goal of this might be the formal adoption of a public engagement philosophy or policy, consistent with recommendations in Cluster A. This work can build on and contribute to the literature on the experiences of other regional boards that have taken on the work of public engagement.

Empirical research into the utility of the workbook will help provide insight into the workbook's effectiveness, and direction about how to maximize this effectiveness. It has been suggested that a workbook of this nature may be akin to "health impact assessments" and "environmental impact assessments". As these may have established procedures, if they are analogous, it will be useful to explore these resources to see what can be learned to advance the workbook. More sophisticated and careful research into facilitating change in how healthcare leaders make decisions will also enable strategic selection of the tools for supporting leaders. Finally, more work in understanding and evaluating forums of engagement, including pre-existing ones, newly created ones, and those aimed at empowering those systemically excluded, will help to improve the support we can offer leaders in nurturing a public sphere around the healthcare system.

Respect for human conscience and intellect has implications for how people are governed: it requires that people's views – views that are knowledge-based and deliberatively developed– inform decisions made on their behalf. It is not a specific type of democracy that respect requires. Rather, respect demands that we strive for the ideals of democracy and the building of democratic competence individually and institutionally.

# BIBLIOGRAPHY

Abelson, J. (2001). Understanding the Role of Contextual Influences on Local Health-Care Decision Making: Case Study Results from Ontario, Canada. *Social Science and Medicine,* 53, 777-793.

Abelson, J., Eyles, J., McLeod, Collins, P., McMullan, C., & Forest, P. (2003). Does Deliberation Make a Difference? Results from a Citizens Panel Study of Health Goals Priority Setting. *Elsevier, Health Policy,* 66, 95-106.

Abelson, J., Forest, P., Eyles, J., Casebeer, A., & Mackean, G. (2004). Will It Make A Difference If I Show Up And Share? A Citizens' Perspective On Improving Public Involvement Processes For Health System Decision-Making. *Journal of Health Services Research & Policy,* 9:4, 205-212.

Abelson, J., Forest, P., Eyles, J., Casebeer, A., Martin, E., & Mackean, G. (2007). Examining the Role of Context in the Implementation of a Deliberative Public Participation Experiment: Results from a Canadian Comparative Study. *Social Science and Medicine,* 64, 2115-2128.

Abelson, J., Forest, P., Eyles, J., Smith, P., Martin, E., & Gauvin, F. (2001). A Review of Public Participation and Consultation Methods. *Health Economics and Policy Analysis Research Working Paper,* 01-04.

Abelson, J., Forest, P., Eyles, J., Smith, P., Martin, E., & Gauvin, F. (2002). Obtaining Public Input for Health Systems Decision-Making: Past Experiences and Future Prospects. *Canadian Public Administration* 45:1 70-97.

Abelson, J., Forest, P., Eyles, J., Smith, P., Martin, E., & Gauvin, F. (2003). Deliberations about Deliberative Methods: Issues in the Design and Evaluation of Public Participation Process. *Social Science and Medicine,* 57(2), 239-251.

Abelson, J., Giacomini, M., Lehous, P., & Gauvin, F. (2007). Bringing 'the Public' Into Health technology Assessment and Coverage Policy Decisions: From Principles to Practice. *Elsevier, Health Policy,* 82, 37-50.

Abelson, J., Gold, S., Woodward, C., O'Connor, D., & Hutchison, B. (2004). Managing Under Managed Community Care: The Experiences of Clients, Providers and Managers in Ontario's Competitive Home Care Sector. *Elsevier, Health Policy,* 68, 359-372.

Abelson, J., Lomas, J., Birch, S., & Veenstra, G. (1995). Does the Community Want Devolved Authority? Results of Deliberative Polling in Ontario. *Canadian Medical Association,* 153 (4), 403-412.

Abelson, J., Mendelsohn, M., Lavis, J., Morgan, S., Forest, P., & Swinton, M. (2002). Canadians' Confront Health Care Reform: A 2002 Survey Shows that Canadians' Attitudes towards Health System Changes are in a State of Flux. *Health Affairs,* 23 (3), 186-193.

Amy, D. Can Policy *Analysis Be Ethical?* In Fischer, F. and J. Forester, Eds. (1987). Confronting Values in Policy Analysis, Sage Publications Inc.

Appiah, K. (2005). *The Ethics of Identity*. Princeton: Princeton University Press.

BC Ministry of Health. (2007). *Summary of the Conversation on Health.* Retrieved December 15, 2007 from http://www.bcconversationonhealth.ca/EN/introduction/

Baocchi, G. (2003). Participation, Activism, and Politics; The Porto Alegre Experiment. In Fung, A., & Wright, E. (eds.) *Deepening Democracy: Institution Innovations in Empowered Participatory Governance.* New York, NY: Verso.

Beauchamp, T., & Childress, J. (2001). *Principles of biomedical ethics: Fifth* edition. Oxford, NY: Oxford University Press.

Beecher, H. (1966). Ethics and Clinical Research. New England Journal Medicine 274 (24): 1354-60.

Bernard, H.R. (1999). *Social Research Methods: Qualitative and Quantitative Approaches.* Sage Publications Inc.

Bohman, J. (1996). Public Deliberation: Pluralism, Complexity, and Democracy. Cambridge, MIT Press.

Bohman, J. (2004). Realizing Deliberative Democracy as a Mode of Inquiry: Pragmatism, Social Facts, and Normative Theory. *Journal of Speculative Philosophy,* 18(1), 23-43.

Bohman, J. and W. Rehg, Eds. (1997). Deliberative Democracy: Essays on Reason and Politics. Cambridge, MIT Press.

Brock, D. (2000). Broadening of Bioethics Agenda. *Kennedy Institute of Ethics Journal,* 10(1), 21-38.

Brook, A. & Stainton, R. (2000). *Knowledge and Mind.* Cambridge: MIT Press.

Buchanan, D. (2000). *An ethic for health promotion: Rethinking the source of human well-being.* Oxford, NY: Oxford University Press.

Burgess, M. (2003). Starting on the right foot: public consultation to inform issue definition in genome policy. *Electronic Working Papers Series.* Vancouver, W. Maurice Young Centre for Applied Ethics, University of British Columbia.

Callahan, D. (2002). *Ends and Means: The Goals for Health Care.* In Danis, M., & Clancy, C. et al., (Eds.) *Ethical Dimensions of Health Policy.* New York, Oxford University Press.

Canada. (1964) *Report of the Royal Commission on Health Services.* (Commissioner E. Hall). Ottawa, Queen's Printer.

Canadian Community for Dialogue and Deliberation. (2008). Retrieved on Feb 14, 2007 from http://www.c2d2.ca/default.aspx?DN=32,Documents.

Canadian Council of Health Services Accreditation (CCHSA). (2002). CCHSA AIM Standards. Ottawa, Author.

Canadian Bar Association Task Force. (1994). *What's Law Got To Do With It? Health Care Reform In Canada.* Ottawa: Author.

*Canadian Medical Association Journal.* (2006). Chaoulli Decision Resonates One Year Later. CMAJ 175(1).

Chambers, S. (2003). Deliberative Democratic Theory. *Annual Review of Political Science,* **6**: 307-26.

Chaoulli *v.* Quebec (Attorney General), [2005] 1 S.C.R. 791, 2005 SCC 35

Cohen, J. (1997). Deliberation and Democratic Legitimacy. In *Essays on Reason and Politics: Deliberative Democracy.* W. Rehg. Boston, MIT.

Cohen, J. (1999). Reflections on Habermas on Democracy. *Ratio Juris,* 12(4), 385-416.

Commission on the Future of Health Care in Canada. (CFHCC). (2002). *Building on Values: The Future of Health Care in Canada, Final Report.* Ottawa

Commonwealth of Learning. (1999). *Designing Open and Distance Learning Materials.* Vancouver, Commonwealth of Learning and Asian Development Bank.

Conole, G., & Oliver, M. (2001). *Decision-Making Resources for Embedding Theory into Practice.*

Conole, G., Oliver, M., & Harvey, J. (2000). *An Integrated Approach to Evaluating Learning Technologies.*

Cook, J., & Oliver, M. (2002). Designing a Toolkit to Support Dialogue and Learning. *Computers and Education, 38, 151-164.*

Daniels, N. (1985). *Just Health Care.* Cambridge, Cambridge University Press.

Daniels, N. (1991). For Unsolved Rationing Problems. *JAMA,* 266(15), 2135-2141.

Daniels, N. (1993). Rationing Fairly: Programmatic Considerations. *Bioethics,* 7 (3), 224-233.

Daniels, N. (2000). Accountability for reasonableness. *BMJ, 321, 1300-1301.*

Daniels, N. (2001). Justice, Health, and Healthcare. *American Journal of Bioethics,* Spring, 1 (2), 2-16.

Daniels, N. (2006). Opportunities and Demands in Public Health Systems: Towards Ethical Review of Health System Transformations. *American Journal of Public Health,* 96(3), 447-451.

Daniels, N. and J. E. Sabin (2002). *Setting Limits Fairly: Can We Learn to Share Medical Resources?* New York, Oxford University Press.

DiMarco M. J. Storch. (1995). History of the Canadian Health Care System. In *The Canadian Health Care System.* ed. Donna Wilson, 5 – 16. Canada: Donna M. Wilson.

Dickinson, H. (2002). How Can the Public Be Meaningfully Involved in Developing and Maintaining an Overall Vision for the Health System Consistent with Its Values and Principles? *Commission on the Future of Health Care in Canada. Discussion Paper 33.*

Donaldson, C., Mitton, C., Martin, H., Hasselback, P., Nelson, D., Dean, S., West, B., & Sommer, S. (2001). *Priority Setting within Regional Funding Envelopes: The Use of Program Budgeting and Marginal Analysis.*

Dryzek, J. (2000). *Deliberative Democracy and Beyond: Liberals, Critics, Contestations*. New York, Oxford University Press.

Dworkin, R. (2000). *Sovereign Virtue: The Theory and Practice of Equality.*

Dwyer, J. (2007). What's wrong with the global migration of health care professionals? Individual Rights and International Justice. *Hastings Centre Report.* September-October.

Emanuel, E. (1991). *The ends of human life: Medical ethics in a liberal polity.* Cambridge, MA: Harvard University Press.

Evans, R. and M. Barer and T. Marmor. (1994). *Why Are Some People Healthy and Others Not? The Determinants of Health of Populations*, Hawthorne, New York: Aldine De Gruyter.

Evans, R. and G. Stoddart. (1990). Producing Health, Consuming Health care. *Soc. Sci. Med.* 31, 12; 1347 – 1363.

Fish, S. (1999). Mutual Respect as a Device of Exclusion. *Deliberative Politics: Essays on Democracy and Disagreement.* S. Macedo. New York: Oxford University Press.

Fishkin, J. (1995). *The Voice of the People: Public Opinion & Democracy.* New Haven, Yale University Press.

Fishkin, J. (2003). Consulting the Public Through Deliberative Polling. *Journal of Policy Analysis and Management, 22 (1), 128-133.*

Fleck, L. (2001). Healthcare Justice and Rational Democratic Deliberation. *American Journal of Bioethics* Spring, Volume 1, Number 2.

Flood, C. (2005). Supreme Disagreement: The Highest Court Affirms an Empty Right. *Canadian Medical Association Journal, 173(2), 142-143.*

Flood, C., & Archibauld, T. (2001). The Illegality of Private Health Care in Canada. *CMAJ,* 164 (6), 825-899.

Fooks, C., & Lewis, S. (2002). Romanow and Beyond: A Primer on Health Reform Issues in Canada. Canadian Policy Research Networks, *Discussion Paper H/05.*

Frankena, W. 1(972). Value and Valuation. In: Edwards P. Editor: *The encyclopedia of Philosophy* NY.

Fung, A. (2003). Associations and Democracy: Between Theories, Hopes, and Realities. *Annual Review Sociology,* 29, 515-539.

Fung, A., & Wright, E. (2003). *Deepening Democracy: Institutional Innovations in Empowered Participatory Governance.* New York, NY, Verso.

Gauvin, F., Abelson, J., MacKinnon, & M., Watling, J. (2006). *Primer on Public Involvement.* Ottawa, Health Council of Canada.

Giacomini, M., Hurley, J., Gold, I., Smith, P., & Abelson, J. (2004). The Policy Analysis of 'Values Talk': Lessons from Canadian Health Reform. *Elsevier, Health Policy,* 67, 15-24.

Gibson, J., Martin, D., & Singer, P. (2004). Setting Priorities in Health Care Organizations: Criteria, Process, and Parameters of Success. *BMC Health Research,* 4 (25), 1-8.

Gibson, J., Martin, D., & Singer, P. (2005). Evidence, Economics and Ethics: Resource Allocation in Health Services Organizations. *Health Quarterly,* 8 (2), 50-59.

Gibson, J., Mitton, C., Martin, D., Donaldson, C., & Singer, P. (2006). Ethics and Economics: Does Programme Budgeting and Marginal Analysis Contribute to Fair Priority Setting? *Journal of Health Services Research,* 11 (1), 32-37.

Goodin, R. (1995). *Utilitarianism as a Public Philosophy.* NY, Cambridge University Press.

Goodin, R. (2003). When Does Deliberation Begin? Internal Reflection Versus Public Discussion in Deliberative Democracy. *Political Studies,* 25, 627-649.

Gutmann, A. and D. Thompson (1996). *Democracy and Disagreement.* Cambridge, Mass., Harvard University Press.

Gutmann, A. and D. Thompson (2004). *Why Deliberative Democracy?* Princeton, Princeton University Press.

Habermas, J. (1984a). *The Theory of Communicative Actions Volume 1.* Boston Beacon Press.

Habermas, J. (1984b). *The Theory of Communicative Actions Volume 2.* Boston Bacon Press.

Habermas, J. (1995). *Moral consciousness and communicative action.* Cambridge, MA: The MIT Press.

Habermas, J. (1996). *Between Facts and Norms: Contributions to a Discourse Theory of Law and Democracy.* Cambridge, MIT Press.

Hadorn, D., (2005). The Chaoulli Challenge: Getting a Grip on Waiting Lists. *Canadian Medical Association Journal,* 173(3), 271-273.

Harman, G. (2000). *Explaining Value and Other Essays in Moral Philosophy.* NY: Oxford University Press.

Health Canada. (2002). *Canada Health Act Overview.* Retrieved October 17, 2007, from http://www.hc-sc.gc.ca/ahc-asc/media/nr-cp/2002/2002_care-soinsbk4_e.html.

Health Canada. (2008). *Public Involvement and Consultations.* Retrieved February 15, 2008, from http://www.hc-sc.gc.ca/ahc-asc/public-consult/index_e.html.

The Health Care Professionals of British Columbia. (n.d.). Retrieved on January 15, 2008 from http://www.crnbc.ca/downloads/671.pdf.

Janis, I. (1982). *Groupthink: Psychological Studies of Policy Decisions and Fiascoes.* Second Edition. New York, Houghton Mifflin.

Jamieson, D. (2003). Method and Moral Theory. In *A Companion to Ethics.*

Jiwani, B. (2001). *An Introduction to Health Ethics Committees.* Edmonton: Provincial Health Ethics Network.

Kahane, D. (2000). Pluralism. Deliberation, and Citizen Competence: Recent Developments in Democratic Theory. *Social Theory and Practice,* 26 (3).

Kahane, D. & von Lieres, B. (2007). Inclusion and Representation in Democratic Deliberation: Lessons from Canada's Romanow Commission. In Cornwall, A. & Schattan Coelho, V. (eds.) *Spaces for Change? The Politics of Citizen Participation in New Democratic Arenas.* London: Zed Books.

Kenny, N. (2002). *What Good is Health Care? Reflections on the Canadian Experience.* Ottawa, CHA Press.

Kirby, J, & Simpson, C. (2007). An Innovative, Inclusive Process for Meso-Level Health Policy Development. *Health Ethics Committee Forum,* 19:2 161-176.

Kotalik, J. (2003). *Addressing Issues and Questions Relating to Pandemic Influenza Planning.* Health Canada, Centre for Infectious Disease Prevention and Control, Population & Public Health Branch.

Kuczewski, M. (1998). Casuistry and Principlism: The Convergence of Method in Biomedical Ethics. *Theoretical Medicine and Bioethics,* 19.

Kuczewski, M. (2002). Two Models of Ethical Consensus, Or What Good is a Bunch of Bioethicists? *Cambridge Quarterly of Healthcare Ethics,* 11, 27-36.

Lambert, T., Soskolne, C., Bergum, V., Howell, J., & Dossetor, J. (2003). Ethical Perspectives for Public Environmental Health: Fostering Autonomy and the Right to Know. *Environmental Health Perspectives,* 111(2), 133-137.

Lenaghan, J. (1999). Involving the Public in the Rationing Decisions. The Experience of Citizen Juries. *Elsevier, Health Policy,* 49, 45-61.

Lewis, S., Estabrooks, CA., Dickinson, H., Dutchak, JJ., Williams, JI., Mustard, C., & Hurley, J. (2001). Devolution to Democratic Authorities in Saskatchewan: An Interim Report. *Canadian Medical Association Journal,* 6(164), 356-357.

Litva, A., Coast, J., Donovan, J., Eyles, J., Shepherd, M., Tacchi, J., Abelson, J., & Morgan, K. (2002). The Public is too Subjectives': Public Involvement at Different Levels of Health-Care Decision Making. *Social Science and Medicine,* 54, 1825-1837.

Lomas, J. (1997). Devolving Authority for Health Care in Canada's Provinces: 4. Emerging Issues and Prospects. *Canadian Medical Association Journal,* 156(6), 817-823.

Lomas, J. (2001). Past Concerns and Future Roles for Regional Health Boards. *Canadian Medical Association Journal,* 164(3), 356.357.

Lomas, J., Woods, J., & Veenstra, G. (1997a). Devolving Authority for Health Care in Canada's Provinces: 1. An Introduction to the Issues. *Canadian Medical Association Journal,* 153(3), 371-377.

Lomas, J., Woods, J., & Veenstra, G. (1997b). Devolving Authority for Health Care in Canada's Provinces: 2. Backgrounds, Resources and Activities of Board Members. *Canadian Medical Association Journal,* 156(5), 669-679.

Lomas, J., Woods, J., & Veenstra, G. (1997c). Devolving Authority for Health Care in Canada's Provinces: 3. Motivations, Attitudes and Approaches of Board Members. *Canadian Medical Association Journal,* 156(5), 669-679.

MacKinnon, M., Pitre, P., & Watling, J. (2007). *A Learning Guide to Public Involvement in Canada.* Ottawa, Canadian Policy Research Networks Inc.

Maddalena, V. (2006). Governance, Public Participation and Accountability: To Whom are Regional Health Authorities Accountable? *Healthcare Management Forum.*

Mansbridge, J. (1999). Everyday Talk in the Deliberative System. *Deliberative Politics: Essays on Democracy and Disagreement.* S. Macedo. New York: Oxford University Press.

Martin, D., & Singer, P. (2003). A Strategy to Improve Priority Setting in Health Care Institutions. *Health Care Analysis,* 11(1), 59-68.

Martin, D., Abelson, J., & Singer, P. (2002). Participation in Health Care Priority-Setting Through the Eyes of the Participants. *Journal Health Services Resolution1 Policy,* 7 (4), 222-229.

Martin, D., Giacomini, M., & Singer, P. (2001). Fairness, Accountability for Reasonableness, and the Views of Priority Setting Decision-Makers. *Elsevier, Health Policy,* 61, 279-290.

Martin, D., Pater, J., & Singer, P. (2001). Priority-setting Decisions for New Cancer Drugs: A Qualitative Case Study. *The Lancet,* 358, 1676-1681.

Martin, D., Singer, P., & Bernstein, M. (2003). Access to Intensive Care Unit Beds for Neurosurgery Patients: A Qualitative Case Study. J. Neurol. *Neurosurgery Psychiatry,* 74, 1299-1303.

Maxwell, J. & Fooks, C. (2002). The Citizens' Dialogue: *Future of Health Care in Canada.*

Maxwell, J., Jackson, K., Legowski, B. Roswell, S. & Yankelovich, D. (2002). *Report on citizens' dialogue on the future of health care in Canada.* Commission on the Future of Health Care in Canada.

Maxwell, J., Rosell, S., & Forest, P. (2003). Giving Citizens a Voice in Healthcare Policy in Canada. *British Medical Journal,* 326, 1031-1033.

McCarthy, T. (1994). Kantian Constructivism and Reconstructivism: Rawls and Hebermas in Dialogue. *Ethics,* 105, 44-63.

McDonald, M. (2001). Canadian Governance of Health Research Involving Human Subjects: Is Anybody Minding the Store. *University of Alberta Health Law Institute.*

McDonald, V. (1977). Participation in the Canadian Context. *Queen's Quarterly* V.84 457-475.

McFarlane, L. (2005). Supreme Court Slaps For-Sale Sign on Medicare. *CMAJ,* 173(3), 269-270.

Mendelsohn, M. (2002). *Canadians' Thoughts on Their Health Care System: Preserving the Canadian Model Through Innovation.* Commission on the Future of Health Care in Canada.

Mitton, C. Patten, S., & Donaldson, C. (2004). Listening to the Decision Makers: Sustainability of PBMA in Alberta. Application *Health Economic Health Policy,* 3 (3), 143-151.

Mitton, C., & Donaldson, C. (2000). Setting Priorities in Canadian Regional Health Authorities: A Survey of Key Decision Makers. *Elsevier, Health Policy,* 60, 39-58.

Mitton, C., & Donaldson, C. (2002). Setting Priorities and Allocating Resources in Health regions: Lessons from a Project Evaluating Program Budgeting and Marginal Analysis (PBMA). *Elsevier, Health Policy,* 64, 335-348.

Mitton, C., & Donaldson, C. (2003a). Resource Allocation in Health Care: Health Economics and Beyond. *Health Care Analysis,* 11 (3), 245-257.

Mitton, C., & Donaldson, C. (2003b). Setting Priorities and Allocation Resources in Health Regions: Lessons from a Project Evaluating Program Budgeting and Marginal Analysis (PBMA). *Health Policy,* 64, 335-348.

Mitton, C., & Donaldson, C. (2003c). Tools of the Trade: A Comparative Analysis of Approaches to Priority Setting the Healthcare. *Health Services Management Research,* 16, 96-105.

Mitton, C., & Donaldson, C. (2004a). Health Care Priority Setting; Principles, Practice and Challenges. *Cost Effectiveness and Resource Allocation,* 2, 1-8.

Mitton, C., & Donaldson, C. (2004b). *Priority setting toolkit: A guide to the use of economics in healthcare decision making*. London, England: BMJ Books.

Mitton, C., & Patten, S. (2004). Evidence-Based Priority-setting: What Do Decision-Makers Think? *Journal of Health Science Research,* 9 (3), 146-152.

Mitton, C., Donaldson, C., & Manderville, P. (2003). Priority Setting in a Canadian Long-Term Care Setting: A Case Using Program Budgeting and Marginal Analysis. *Canadian Journal on Aging*, 22 (3), 311-321.

Mitton, C., Donaldson, C., Waldner, H., & Eagle, C. (2003). The Evolution of PBMA: Towards a Macro-Level Priority Setting Framework for Health Regions. *Kluwer Academic Publishers,* 6, 263-269.

Mitton, C., Patten, S., Waldner, H., & Donaldson, C. (2003). Priority Setting in Health Authorities: A Novel Approach to a Historical Activity. *Social Science and Medicine,* 57, 1653-1663.

Mitton, C., Peacock, S., Donaldson, C., & Bate, A. (2003). Using PBMA in Health Care Priority Setting Description, Challenges and Experience. *Open Mind Journals Ltd.2* (3), 121-134.

Mullen, P. (1999). Public Involvement in Health Care Priority Setting: An Overview of Methods in Eliciting Values. *Blackwell Science Ltd,* 2, 222-234.

National Forum on Health (NFH). (1997). *Canada Health Action: Building on the Legacy. Values Working Group Synthesis Report.* Ottawa, Health Canada.

Narveson, J. (1988). *The Libertarian Idea.* Philadelphia: Temple University Press.

Nevitte, N. (1996). *The Decline of Deference: Canadian Value Change in Cross-National Perspective.* Peterborough, Broadview Press.

Nozick, R. (1974). *Anarchy State and Utopia.* New York, Basic Books.

Oliver, M., & Conole, G. (2000). Assessing and Enhancing Quality Using Toolkits. *MCB University Press,* 8 (1), 32-37.

Outellet, R. (2005). The Chaoulli Decision: A debate in Which Physicians Must be Heard. *JMAC,* 173(8), 896.

Pal, L. (2001). *Beyond Policy Analysis* (2nd ed.*).* Scarborough: Nelson Thomson Learning.

Patton, M. Q. (1990). *Qualitative Evaluation and Research Methods* (2nd ed.). Newbury Park, CA: Sage Publications, Inc.

Pauly, B. (2004). Shifting the Balance in the Funding and Delivery of Health Care in Canada. In Storch, J, Rodney, P., & Starzomski, R. (Eds.) *Toward a Moral Horizon: Nursing Ethics for Leadership and Practice.* Toronto, Pearson Education Canada, Inc.

Peacock, S., Ruta, D., Mitton, C., Donaldson, C., Bate, A., & Murtagh, M. (2006). Health Economics: Using Economics to Set Pragmatic Ethical Priorities. *British Medical Journal,* 332, 482-485.

Pettit, P. (2001). Deliberative Democracy and Discursive Dilemma. *Philosophical Issues,* 11, 268-299.

Pivik, J. (2002). Practical Strategies for Facilitating Meaningful Citizen Involvement in Health Planning. *Commission on the Future of Health Care in Canada, Discussion Paper 23.*

Price, D. (2000). Choices Without Reason: Citizens' Juries and Policy Evaluation. *Journal of medical Ethics,* 26, 272-276.

Public Health Agency of Canada. (2006). *Highlights from the Canadian Pandemic Influenza Plan for the Health Sector* Retrieved Feb 17, 2007 from http://www.phac-aspc.gc.ca/cpip-pclcpi/hl-ps/index-eng.php#in.

Rawls, J. (1971). *A Theory of Justice.* Cambridge: Harvard University Press.

Rawls, J. (1993). *Political Liberalism. The John Dewey Essays in Philosophy, 4.* New York: Columbia University Press.

Reeleder, D., Goel, V., Singer, P., & Martin, D. (2006). Leadership and Priority Setting: The perspective of Hospital CEO's. *Science Direct, Health Policy,* 79, 23-34.

Reeleder, D., Martin, D., Keresztes, C. & Singer, P. (2005). What do Hospital Decision-Makers in Ontario, Canada, Have to say about the Fairness of Priority Setting in their institutions? *BMC Health Services Research,* 5 (8), 1-6.

Ross, W. (1930). *The Right and the Good.* Oxford University Press.

Rowe, G., & Frewer, L. (2000). Public Participation Methods: A Framework for Evaluation. *Science, Technology and Human Values,* 25(1), 3-29.

Ruta, D., Mitton, C., Bate, A., & Donaldson, C. (2005). Programme Budgeting and Marginal Analysis: Bridging the Divide Between Doctors and Managers. *British Medical Journal,* 330, 1501-1503.

Sheldon Chumir Foundation for Ethics in Leadership, (n.d.). Retrieved on December 12, 2007 from http://www.chumirethicsfoundation.ca/main/page.php?page_id=1.

Sherwin, S. (1998). Relational Autonomy in Sherwin, Sue Ed. *The Politics of Women's Health: Exploring Agency and Autonomy.* Philadelphia: Temple University Press.

Singer, P., Martin, D., Giacomini, M., & Purdy, L. (2000). Priority Setting for New Technologies in Medicine: Qualitative Case Study. *British Medical Journal,* 321, 1316-1319.

Skogstad, G. (2003). Who Governs? Who Should Govern?: Political Authority and Legitimacy in Canada in the Twenty-First Century. *Canadian Journal of Political Science,* 36(5), 955-973.

Soskolne, C. & Light, A. (1996). Towards ethics guidelines for environmental epidemiologists. *The Science of the Total Environment,* 184(1,2):137-147. Also accessible at: http://www.iseepi.org/about/ethics.html

Soskolne, C. (2003). Integrating principles derived from human rights, bioethics, and sustainable development for healthy public policy on indoor air. *Health Ethics Today* 13(2): 8-11.

Syrett, K. (2003). A Technocratic Fix to the "Legitimacy Problem"? The Blair Government and Health Care Rationing in the United Kingdom. *Journal of Health Politics, Policy and Law,* 28(4), 715-746.

Teng, F., Mitton, C., & MacKenzie, J. (2007). Priority Setting in the Provincial Health Services Authority: Survey of Key Decision Makers. *BMC Health Services Research,* 7 (84), 1-10.

UBC Centre for Health Services and Policy Research. (2007). *Voices and Choices: Public Engagement in Health Care Policy. A summary of the 2007 health policy conference of the UBC Centre for Health Services and Policy Research.* Vancouver, Author.

University of Toronto Joint Centre for Bioethics Pandemic Influenza Working Group. (2005). *Stand on guard for thee: Ethical considerations in preparedness planning for pandemic influenza.*

Veatch, R. (1986). *The Foundations of Justice: Why the Retarded and the Rest of Us Have Claims to Equality.* New York: Oxford University Press.

Walton, N., Martin, D., Peter, E., Pringle, D., & Singer, P. (2006). Priority Setting and Cardiac Surgery: A Qualitative Case Study. *Science Direct, Health Policy 80,* 444-458.

Wilson, D. (1995). (Ed.) *The Canadian Health Care System.* Canada. Author.

Young, I. (1996). Communication and the Other: Beyond Deliberative Democracy. *Democracy and Difference: Contesting the Boundaries of the Political.* S. Benhabib. Princeton, Princeton University Press.

Young, I. (1999). Justice, Inclusion and Deliberative Democracy. *Deliberative Politics: Essays on Democracy and Disagreement.* S. Macedo. New York, Oxford University Press.

Young, I. (2000). *Inclusion and Democracy.* Oxford, Oxford University Press.

Young, I. (2001). Activist Challenges to Deliberative Democracy. *Political Democracy,* 29 (5), 670-690.

# APPENDIX A: THE DEVELOPMENT OF THE CANADIAN HEALTH SYSTEM

Early in Canada's history, health was largely considered a matter for individual, family, church, or community concern. Government agencies were seen to be responsible only for epidemics of illness, the insane, the orphaned and other situations where the care required was beyond the family's or community's means to provide (DiMarco & Storch, 1995 p.6). In the period after Confederation in 1867, a belief began to grow that the government ought to have a greater role in promoting individual health – understood at the time in terms of providing healthcare services. As early as 1919, federal political parties had made policies for health insurance part of their platform of values (Canadian Bar Association (CBA), 1994, p.3). The prosperity of the 1920s brought increasing numbers of government health and social programs (DiMarco & Storch, 1995 p.7). Then in the 1930s, with the development of international statements of human rights and freedoms, the development of health and social programs in other countries, and particularly the onset of the Great Depression, the federal government began thinking about long-range health and social programs (Ibid. p.8).

DiMarco and Storch (Ibid.) argue that the 1930's depression in particular had an important impact on this development because people began to realize that illness could bring disaster to anyone through no fault of their own. However, accessing healthcare services involved either seeking care from private providers and facilities, which in turn usually meant having to pay user fees, or finding a charitable organization that would provide services without charge. Consequently, this option was not available to any but the rich who could afford it and the very poor who were able to access services for free.

As a result, social consensus began to develop that those left without access to services ought to be provided for. This realization suggests that from early on Canadians have felt that it is unfair for hardship to be distributed arbitrarily and that collective measures ought to be taken to ameliorate such inequity. In fact, a committee formed by the Canadian Medical Association suggested in 1934 that, "government health insurance was necessary and, in view of the obvious interest of the public in it, probably inevitable" (CBA, 1994 p. 4).

Then in 1942 a committee was appointed by the federal government to look into the views of a number of national organizations on the issue of health insurance. Among those groups consulted were a number of trade unions, healthcare provider associations and the National Council of Women Ibid.). The committee found that most groups surveyed were in favour of provincial health insurance programs with government support. This further demonstrates that the values of the Canadian people at the time favoured programs to help those seen as arbitrarily affected by an indiscriminate hardship. That the health insurance program favoured was government run and universal suggests that people were concerned with providing these programs to all who needed them, equally.

By the post war period both the federal and provincial governments were already seriously debating healthcare insurance Ibid. p.5). After a failed post-war conference on reconstruction in 1945, the province of Saskatchewan passed the Saskatchewan Hospitalization Act in 1947 (DiMarco & Storch, 1995 p. 9 & 14). This legislation assured that all members of the province in need of hospital services would be provided with it, regardless of their ability to pay.

The legislation paved the way for national hospital insurance, which came in the form of the federal *Hospital Insurance and Diagnostic Services Act* in 1957 (Ibid.). Under this legislation, the federal government would share the costs of provincial insurance programs for hospital care and diagnostic services in which all citizens of that province were eligible. By 1961, all provinces had joined the federal plan and could boast provincial hospital insurance programs (CBA, 1994 p.6).

The provincial government of Saskatchewan, again leading the way, took the next major step on the path to a national Medicare program. In 1959 it announced its intention to create universal healthcare insurance, which was to cover care by physicians and surgeons. To this point, the fees for these practitioners were still not included in any legislated insurance program (DiMarco and Storch, 1995 p. 10, CBA, 1994 p. 6). The announcement came just before a provincial election and became an important election issue. In the election, the incumbent government received the popular support and was reinstalled. The result: in 1961 the *Saskatchewan Medical Care Insurance Act* was passed (Ibid.).

However, at this point the Canadian Medical Association, in favour of health insurance generally, but long opposed to universal coverage because of the limits it might place on the providers' remuneration for services, asked the federal government to examine the matter of universal healthcare coverage (CBA, 1994 p. 7). The hope was that a system of universal care would be found unnecessary and overly infringing on physician autonomy. Soon after, the government did appoint a Royal Commission to investigate the issue. The commission, headed by Justice Emmett Hall, released its report three years later, in 1964. The report suggested that, "as a nation we now take the necessary legislative, organizational and financial decisions to make all the fruits of health sciences available to all our residents without hindrance of any kind. All our recommendations are directed towards this objective" (Canada, 1964-65 p. 10). The reaction of the Hall Commission to the concerns of the CMA provides further support to the claim that Canadian values cohere with liberal egalitarian ideals.

The report of the Royal Commission set the stage for the passing of the *Medical Care Act* by the federal government in 1966 (CBA, 1994 p.9-10). This legislation would have the federal government covering fifty percent of the costs of physician services in any province where the insurance program met certain criteria set out in the Act. These criteria included that the coverage be to a comprehensive set of services, be portable through any province, be universal in providing coverage to at least 90% of citizens, and be publicly administered through a not-for-profit agency (Ibid.).

Once again, this series of developments demonstrates that the people of Saskatchewan in particular, and Canadians in general, favoured universal healthcare insurance coverage – providing support for people in hardship commensurate with need, at least when the hardship was randomly distributed.

The next step in the process leading up to the *Canada Health Act* came in 1977 with the passing of the federal *Federal-Provincial Fiscal Arrangements and Established Programs Financing Act* (Ibid. p. 10, DiMarco and Storch, 1995 p. 10). The federal government was feeling the cost burden of financing half of the expense of provincial programs. This Act altered the way in which the federal contribution was calculated. It went from a percentage of the costs to a provincial per capita grant to be adjusted with economic growth. The result would be lower federal health expenditures and greater provincial fiscal responsibility for healthcare programs.

The 1977 Act would create an important challenge to national healthcare insurance. For with the decrease in federal funding for health care, extra-billing by healthcare providers became a reactionary issue. Canadians were faced with the prospect of having to pay once again out of pocket for healthcare services. However, because of the popularity of the national Medicare system and other political, economic and public pressures, the federal government created legislation that affirmed with some force the value of a national healthcare insurance scheme. This legislation was the *Canada Health Act* of 1984 (CBA, 1994 p. 11; DiMarco and Storch, 1995 p. 11).

This Act essentially combined the universal coverage of hospital services from the 1957 Act and the universal health care coverage of the 1966 Act. However, it added two very important features (Ibid.). First of all, in addition to restating the importance of the four principles required of provincial programs in the 1966 Act, those of comprehensiveness, portability, universality and public administration, it added a fifth and telling principle – that of accessibility. This fifth principle explicitly addressed the question surrounding the acceptability of extra-billing for healthcare services. The practice was deemed not acceptable according to federal government standards. Provincial healthcare programs "must provide for insured health services on uniform terms and conditions and on a basis that does not impede or preclude, either directly or indirectly whether by charges made to insured persons or otherwise, reasonable access to those services by insured persons" (Wilson, 1995 p. 101). Secondly, the Act empowered the federal government to enforce adherence to the criteria by the provincial programs.

The Act allowed for the federal government to withhold its payments, imposing a dollar-for-dollar penalty, to any province not following any of the five principles.

This response of the federal government to the concerns raised over extra billing and the great public support for the Act together provide still further evidence of the value placed by Canadian people on the equality of persons. In the words of DiMarco and Storch, "Canadians at last had the security of publicly funded, good quality, comprehensive health care. Access to health care for all Canadians supported a strong social value of equality (DiMarco and Storch, 1995 p. 11)."

# APPENDIX B: A WORKBOOK FOR SYSTEMS-LEVEL DECISION-MAKING

Practical Tools for Values-Based System-Level Decision-Making

DRAFT

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## Introduction

System-level decisions in health care are those decisions that immediately impact more than just a single patient or resident, their loved ones, and a particular team of care providers. They range from government boardroom decisions about system structure and payment for services to ward and program decisions about staff scheduling and workload distribution.

In the complex world of modern health care where there is so much at stake for so many of us, those responsible for making such decisions increasingly recognize that these decisions are not simply objective calculations about value-free evidence, but rather subjective exercises where the best solution will vary depending on one's perspective. The process of reflecting on different perspectives and critically engaging the question, what values should guide this decision is the work of ethics. The goal of this workbook is to provide support for decision-makers who recognize and wish to take seriously the ethics dimension of their work.

### *Outline*

The book is broken into two parts. Part One begins with a description of two case studies and then elaborates the role of each the above four dimensions in the two cases. The case studies have to do with the allocation of scarce resources at the program level and decision-making in the context of influenza pandemic planning. It then provides some broad reflections on ethics in general and conceptual tools for thinking particularly about how ethics relates to system-level decision-making in health care. These introductory remarks lead into the identification of four ethics dimensions of system-level decision-making in the health context: 1) the relationship among the decision-makers and the integrity of the decision process itself, 2) the nature of the public engagement that informs the process, 3) the nature of the staff consultation that informs the process, and 4) attention to those affected by the decision, including support for those who may be placed in ethical difficulty as a result of the decision.

In Part Two, practical directions are offered to decision-makers. It begins with formal commitments that leadership must consciously make if it seeks justified system-level decisions. After this a discussion of decision frameworks and processes is offered followed by a formal decision-making framework. Here the four dimensions are incorporated into one ideal decision process that can be used by decision-makers at all levels. The ideal process is described and suggestions are made for how this ideal process might be adjusted for everyday use in the busy and demanding work lives of health professionals. A decision tree that captures the essence of the framework in a few steps and a set of worksheets that readers can use to tackle the case studies or examine their own system-level decisions are also provided in this section. Then guidance the development of a public engagement philosophy and consultation strategies are described. The section ends with a suggested organizational policy on policies and a decision checklist for reviewing the justification of decisions made.

A glossary of the procedural and substantive values that are likely to be considered important in the healthcare context are added at the end of the book.

### *How To Use This Guide*

The purpose of this workbook is to offer an ideal decision process that responds to all four ethics dimensions of system-level decision-making. And ideally, decision-makers would read through the entire book before using the tools in actual decision contexts.

However, the reality is that for busy decision-makers, something needs to offer real promise of making life easier and/or more productive if they are to invest precious time in learning it. Additionally, understanding of the theory behind the process is not, strictly speaking, necessary to reap the benefits of the process.

Accordingly, for decision-makers who have a specific issue they are looking for support with, it is recommended that decision-makers go straight to the section in Part Two entitled Values-Based Decision Process for Teams. Here a process is provided that any team can use to go through any issue in a window of 30 to 90 minutes, depending on the experience of the team, the complexity of the issue, and the resources available to make a decision as thoughtfully as possible.

## Case Studies

### *Influenza pandemic planning*

#### *Overview of the Influenza Pandemic*

It is expected that the next in a cycle of global influenza pandemics can be expected in the near future. The following is excerpted from the British Columbia Ministry of Health BC Health Files website (http://www.bchealthguide.org/healthfiles/hfile94a.stm).

What is influenza?

Influenza, or the "flu," is a common respiratory disease caused by a virus. Every year, the flu virus causes outbreaks in fall and winter. This is because each year, the flu virus changes a little so the protection, or immunity, our bodies have built up against previous viruses is not as effective.

The flu spreads easily from person to person through coughing and sneezing and hands touching your eyes, mouth or nose. Flu symptoms can appear suddenly and include a fever, cough, fatigue, headache, muscle pain, a runny nose and a sore throat. The worst symptoms usually last about five days, but coughing can last up to two to three weeks. Sometimes children with the flu can have nausea, vomiting or diarrhea.

Although colds and other viruses may cause similar symptoms, influenza weakens a person more than other viruses. About 20 per cent of persons infected will not have any symptoms. In others, symptoms can be mild to severe. However, if infected, very young children, people with some chronic medical conditions and the elderly are more likely than healthy older children or adults to get very sick, and may need to be hospitalized. In Canada up to 7000 people die each year from influenza or its complications. People over 65 years are at the greatest risk of dying from the flu.

How is pandemic flu different?

Flu pandemics happen when a new kind of influenza virus, that is able to spread easily from person to person appears, and spreads quickly around the world. Since people have no protection against the new virus, it will likely cause more illnesses and a larger number of deaths than the seasonal flu.

Influenza pandemics have happened every ten to forty years for at least the last 500 years. There were three flu pandemics last century, the last in 1968. The most severe – often called the "Spanish Flu" pandemic – was in 1918. No one can predict exactly when a pandemic will happen, but it may be soon. That is why people and communities must prepare now, to ensure they are ready to respond when needed.

How will BC know that a flu pandemic is coming?

A flu pandemic will likely begin outside North America. A worldwide network of scientists, including scientists in Canada and BC, closely tracks flu activity. This cooperation will help to identify a new flu virus that could cause a pandemic, as early as possible.

What will happen in BC?

Based on past pandemics, it will take no longer than six months from the start of a flu pandemic somewhere in the world until the time that same flu causes outbreaks in BC. Because airline travel is much more common now than ever before, this timeline could be much shorter.

BC has had an alert system in place for a long time, and it has been very effective in the past for identifying illnesses, such as Severe Acute Respiratory Syndrome (SARS). It includes asking health care workers across the province to report any new or unusual illness in travelers either coming or returning to BC. This system will ensure early testing and provide early warning to health officials when the virus that causes pandemic flu has reached BC. When a virus that can cause a flu pandemic has been found in BC, the Provincial Health Officer will inform the public.

The BC Pandemic Influenza Preparedness Plan lays out steps and ways that BC can prepare for a flu pandemic before it arrives, and respond to the pandemic once it is here. The Plan's key goals are to help communities and their resources to work together to reduce sickness and death, and give families and groups tips and ways to stay well and secure. Check with your local health authority for more information.

Unlike other natural disasters like tsunamis, floods or earthquakes, once a flu pandemic arrives, it could last for several months. It is most likely that a pandemic will strike hardest during the usual flu season, which is December to March. It is also likely that a pandemic will occur in several waves, with the second wave of illness occurring within six to nine months after the first. This means people need to be prepared to respond not only once, but several times.

When a flu pandemic reaches BC, it may make people sick in different parts of the province at different times. More people might get sick in one city than in another. There is no way to know for sure how many people will get sick or die in the next pandemic.

What can you expect where you live?

During a flu pandemic, more people will be sick at the same time than normal, and it will be harder for the health system to keep up. Based on United Kingdom models of illness rates during a pandemic, it is estimated that at its peak, 10 per cent of persons or more will be ill enough to be off work during any one week. Because more people will be sick, you might have to wait longer to see your doctor or get into a hospital. Because more people will be off work with the flu, there may be problems in other types of services, like garbage pick-up, bus service, and being able to buy food.

There are plans in place to help people during a pandemic. For example, you can expect that:

- The most needed medical services will still be provided;
- Special clinics may be set up specifically to treat people with flu or flu-like illness; and
- People with the worst symptoms and those who are most likely to get very sick or die from the flu will be cared for.

These estimates cited above are very conservative. Indeed many expect that over an eight to 12 week period, the virus will infect 35% of the population resulting in the equivalent of in increase in visits to the emergency departments by a volume that equals half of the usual annual number of visits.

Planning for the possible arrival of a pandemic is taking place across the globe. Beginning with the World Health Organization and through to various national and regional levels, almost every governing body is developing some plan to prepare should a pandemic strike. Planning areas include surveillance, vaccine delivery, emergency preparedness, communications, health services and clinical guidelines.

## ***Issues***

Each aspect of a plan like that for the influenza pandemic preparedness can be seen as a system-level decision. Accordingly each of the decisions within the plan can be evaluated from an ethics perspective: is the decision based on good information (facts/beliefs) and the right considerations (values)?

For example, when it comes to vaccine delivery, who will receive the vaccinations? If the goal is to vaccinate 75% of the population, why do we value the lives of those who do get vaccinated above the lives of those who do not? Who do the vaccination strategies that we employ favour and how do we justify this? What special attention is paid to vaccinating the most vulnerable groups in our society?

When it comes to anti-virals procurement and distribution, what will be stockpiled? Who will receive these resources? When will they be distributed – as prophylactics?

In terms of emergency preparedness, is it important to save as many lives as possible, or to save the lives of those most at risk? What are the values that justify the plan's response to this question? What measures will be put in place to ensure that similarly situated individuals will be treated similarly in the time of emergency? How is "societal disruption" defined in the emergency preparedness framework? Which of the everyday services that might be jeopardized by a pandemic are considered the most important? Why? What values justify this position? If emergency response depends upon individual families, businesses etc. identifying the emergency and requesting assistance, and if care for the vulnerable is a key value (as described) then what barriers exist to such individuals recognizing emergencies and accessing emergency help? How will these be overcome? What proportion of resources is devoted to vulnerable populations and how is this justified? What values inform the position that "public safety is paramount", and what does this mean? Who (i.e. whose values) will be involved in the municipal decision-making about what businesses and services count as crucial to keeping open at the time of emergency?

When it comes to communications, what values will govern the communication strategy that is employed? (Accuracy, consistency, timeliness?) To what extent are these genuinely manifest in the communication policy? What notion of honesty is valued in the plan? Is it anticipated that the choice between potentially creating panic in the community and providing accurate information for individual decision-making arise and if so, what values will the choice be made according to? To what extent will political expediency impact the nature and type of communication that takes place and how will this affect stated values? How will those who do not readily access mainstream media (due to language barriers or disabilities, for example) be addressed in the communication plan? What values justify special attention to these groups?

About health services, in light of the expectation that resources will lag far behind need for services, and the commitment to providing the best possible care to citizens, what resource allocation guidelines will be used to direct who will receive care and what kinds of care will be offered in the emergency? What values inform these guidelines? Who will make resource allocation decisions, and what ethical decision-making training will these individuals receive?

What values will inform the "appropriate infection control guidelines used to reduce the spread of infection"? What values will these guidelines offend and how will this be justified? If accountability requires that we only demand of professionals what they have the expertise to do in light of the training and support resources we provide, what kind of accountability will we demand from the various types of healthcare providers that we will have to employ? What, if any, confidentiality issues are associated with the information collection, analysis and dissemination efforts that will be required? What, if any, cultural sensitivity issues might we face in providing health care services in emergency situations and how will these be addressed? What, if any, arrangements will be made to meet the health needs of those with physical disabilities? What values justify special attention to these groups?

As for clinical guidelines, what values are the triage guidelines based upon? Whose values should be reflected in the triage guidelines? Have the values of these groups been adequately considered? What ethics resources will be available to deal with situations of moral uncertainty and conflict? Who will be able to access these resources? How will these individuals know about the availability of these resources? What resource allocation guidelines will be employed and what values will these be based upon? What ethical decision-making training will decision-makers be given?

Another very challenging area will be the allocation of human resources, identification of crucial roles during a pandemic and work relative to scope of practice. When there are three times the number of patients presenting for acute care, and one third of the work force available to provide services, which functions should be seen as crucial and which secondary? Is it more important for communications and finance staff to perform their usual functions, or should they be in hospital delivering trays and moving patients? And how will staff be allocated to meet basic needs? Should neurosurgeons be asked to serve as primary care docs at an alternate care site?

Don't Panic!

This list is incredibly daunting – and it's not nearly complete. If you're on the planning team, don't worry – it'll be OK. One central benefit of ethics analysis is that it provides us with a way forward. The idea is that once we understand the inescapably ethical nature of the many decisions we face, we can start using the tools provided in this book to clarify what values should guide the decisions and how we can move towards making the best decisions, all things considered.

### *One Example: A Policy on Human Resources*

It is important to start somewhere. So let's pick one decision, use the tools and see where it takes us. A good example might be the decision about human resource policy.

Health regions will need to develop a system-level response (policy or guideline) to support managers in dealing with potential staff shortages during a pandemic. Health leaders are responsible for ensuring that sufficient numbers of people with required skills and experience are available to provide care. The reality of the situation is that a large majority of nurses and care providers are women and that they may have children and elderly parents that they are caring for. If the pandemic hits as we anticipate they may be called into work but the resources they usually use in caring for their family members while they are at work may not be available.

They will face decisions of the following type:

A married mother of three works as a nurse at the local hospital. A Pandemic alert has been issued and she is called into work. The following day, she notices her eldest son has become ill with symptoms suggestive of influenza and her husband has also fallen ill. She is called into the hospital again.

A woman who is a respiratory tech with much unique skills and expertise is called into the hospital. However, her husband is gravely ill with terminal cancer, expected to live only 4-6 weeks. She's been on compassionate leave, but is needed at the hospital.

### *Meso-Level Resource Allocation In Health Care*[66]

You are a member of the executive for a health region charged with the responsibility of providing health care services for a population of 500,000. The province has frozen your budget from the previous year and all efforts at increasing efficiencies and resource development have been exhausted. You are running a deficit and some of the new programs you have are not fully funded. So your executive team must eliminate six million dollars from your budget. Aside from the announcement for funding, the government has offered no direction as to what priorities the region should have. (Quite unlike the usual situation!) Key environmental issues include serious demand pressures on beds, congestion in emergency departments, and unfunded bed capacity in community care.

The programs listed below have already been approved for funding, but have been reluctantly identified as candidates for elimination by various members of the executive through a painful process of consultation with the various regional departments.

The total cost of all programs would be approximately $15 million, but only $5 million is available to support them. How would you allocate the money *among these programs*? (So no outside the box thinking for this exercise!) What criteria did you use to judge the value of the different programs?

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[66] Prepared by Bashir Jiwani (2006). Adapted from Larry Churchill, *Rationing Healthcare in America*. Indiana: University of Notre Dame Press. 1987. Acknowledgements to Bark Kong, Patricia Petryshen, and Brian Woods, Fraser Health.

| Program | One time cost | Annual operating cost | Total this budget cycle | Your allocation |
|---|---|---|---|---|
| Hiring of extra personnel, particularly nurses, for understaffed areas in acute care and home care where there are more patients than funded beds and patients of higher acuity than historically seen. | 0 | 2m | 2m | |
| Increasing the region's continuing education budget for home care nurse training for palliative care and a healthy beginnings program for early maternity discharge follow-up. | 0 | 250k | 300k | |
| New initiatives to decrease waits in emergency rooms in each hospital in the region. | 3m | 1m | 4m | |
| Increase funding to the orthopedic surgery program to shorten waiting lists for hip replacement surgery. (Waiting list is currently 10 – 12 months.) | 0 | 1.5m | | |
| Expand services for the vulnerable elderly to provide nutrition, social support, and accident/injury prevention services. | 0 | 1m | 1m | |
| Improve access to health services for minority (native and religious communities) populations in your region. Minority groups presently have morbidity and mortality rates 10-15% higher than the population average and make up 22% of the region's population base. Services required include care programs as well as information and translation services. | 1.5m | 750k | 2.25m | |
| Create the equivalent of three new full time positions to allow physicians to take on administrative responsibilities in regional management. | 0 | 750k | 750k | |
| Hiring new staff to ensure quality improvement personnel are available at all sites. | 0 | 500k | 500k | |
| Capital expenditures including building repairs to hospitals, without which patient and staff security is threatened. | 0 | 2m | 2m | |
| Total | 4.5m | 9.75m | 14.25m | 5m |

## Part One: Things to Think About

## How to Speak Ethics

### *Some Assumptions*

It is a commonplace understanding that ethics is roughly about right and wrong, good and bad. However, when it comes to more specific questions about what makes something right or wrong what the appropriate subject matter is for examining from an ethics perspective, what the appropriate sources of moral authority are, and how decisions should be made, a commonplace understanding does not exist.

Moreover, and perhaps because of the diversity of answers to these questions, we lack a shared language for discussing the ethical dimensions of the individual and collective decisions we must make in our lives. But having such a shared language is crucial, as whether individual or collective, almost all of the decisions made every day do have an impact on others. This resource suggests and recommends one way of talking about ethics, particularly in the context of system-level decision-making within the health system.

The workbook assumes that all our attitudes, decisions and actions are based on two important types of ideas: beliefs and values. "Beliefs" are thing that we take to be true about the world – the facts, as it were. "Values" are the things that we think are important – things that we value. It will be easier to illustrate this with an example.

### *One Example: Protecting Lab and Health Care Workers During a Pandemic*

As organizations plan for the eventuality of an influenza pandemic, one question they will encounter is, how and to what degree should laboratory technicians and other care and service providers be protected against the possibility of contracting the influenza virus.

Looking at what happened during the SARS experience, many decision-makers may choose to offer care providers with the n95 mask and also anti-viral therapy as part of an appropriate protection scheme. They believe that the n95 mask will prevent airborne viral particles from contacting the care provider. And they believe that existing anti-viral drugs will help the body fend off the virus, should it penetrate the body.

The first thing to notice is that all of these statements are assumptions about "the facts". They are conditional statements about what consequences will result from various actions. We can usually tell when someone is describing the facts of the world as they see them when they use various formulations of the verb "to be". "This *will* happen" is a statement of fact. And "facts" of course may or may not be true.

The second thing to notice is that these facts often rest on other facts. The fact or belief that the n95 mask will prevent airborne particles from contacting the wearer rests on beliefs about how the virus is transmitted. The fact or belief that existing anti-viral drugs will help the body fend off the virus rests on the belief that the flu bug that will hit the world will be such that existing anti-virals will be effective.

Another thing to notice is that facts alone do not provide enough information about what the right decision in any situation is. The facts must be evaluated from the perspective of what is important in the situation – which relates to broader notions of what is important in life.

Believing the above "facts" about masks and anti-virals is not enough to justify the decision to provide them to all care providers. Decision-makers who choose to provide these protective resources to care providers might do so in order to protect worker health, build worker trust, minimize overall cost to the system, provide most care possible to society, provide best care possible, minimize spread of disease, and minimize risk of death. They find these considerations to be very important. It is our values – the considerations we think are important and should guide conduct – interpreted against the context of the world as we believe it to be, lead us to our judgments about what decisions, actions and attitudes should constitute our behaviour.

## *Ethics – A Working Approach*

In our example, all we have done is described a perspective. We have speculated on the beliefs and the values that decision-makers who choose to provide n95 masks and anti-viral drugs to care providers might have. We have not critically engaged the question, should decision-makers provide these resources to their physicians, staff and volunteers?

Ethics, on the approach recommended here, is about critically examining the values and beliefs that our decisions, actions and attitudes are guided by. It involves thinking about what we have good reason to accept as fact, and what we have good reason for holding as important. In other words, ethics is about evaluating whether our decisions, actions and attitudes are based on facts that we have good reason to think are true, and values that we have good reason to cherish. An ethically justified decision, action, or attitude is one that is based on facts we have good reason for believing to be true and relevant, and considerations we have good reason to hold as the most important in the situation.

The work of ethics can be broken down into three different activities. The first activity involves reflecting on behaviour and asking, what does this decision say about what I believe and what is important to me? This is called descriptive ethics because it is an effort to describe (without judging) the values underpinning behaviour.

The second type of ethics work requires that we ask, what are the values that we should live by – that we want our own and others' behaviour to be guided by? This type of ethics work is called prescriptive or normative ethics because it offers direction on how the world should be.

The third activity of ethics involves bringing our attitudes and actions in line as much as possible with our cherished values. When one is interacting in the world and has to decide what to do or how to act, this activity involves thinking about how to practically base a decision, action or response on the values that we should be living according to. This is practical or applied ethics because it concerns the application of our values to daily life.

We – as individuals and as organizations – can then use this information to evaluate *upcoming* decisions and ask what are the beliefs and values that should inform the decision. And we can examine *past* decisions that we have made to see whether they are based on justified beliefs and values. Most valuably, we can then tailor our responses to life – our decisions, actions and attitudes – to best reflect our values and beliefs.

### ***Our Example Revisited***

In our example the work of ethics is to ask, is the decision to provide n95 masks and anti-viral drugs to care providers as part of a protection scheme justified? To answer this we would want to know a) whether we have good reason to hold our beliefs about the situation. So will the masks actually prevent the influenza virus from coming into contact with wearers? Will it do so better than ordinary masks? Will anti-viral therapy actually be effective on the flu virus that is expected? How will the virus be transmitted? Will trust actually be built by providing these resources to workers? What is the perception of workers about the effectiveness of these resources? What is the expectation of workers about receiving these resources?

And we would want to know b) what should decision-makers hold as most important when it comes to what scheme of protection should be offered to workers? Should concerns about the health of workers be most important? Or should concerns about trust between workers and the organization be most important? Or should financial cost be most important?

How well these questions are answered will determine the justification of the decisions made. If the decision about what to provide is based on sound evidence – facts we have very good reason to think are true – and on a very well-considered and defensible set of values will be more ethically justified. Decisions made on a poor understanding of the facts and/or on values that have not been carefully considered and exposed to critical scrutiny will be on the ethically unjustified side of the scale.

### ***Intrinsic/Inherent and Instrumental/Strategic Values***

One way to help understand how the basic values that guide our everyday decisions connect with the broader values is to think about the distinction between instrumental values and intrinsic values.

Instrumental or strategic values are those that are important to us because they give us something that is even more important to us. For example, we may decide that what is important to us when determining what goes into a worker protection scheme in pandemic planning is providing workers with whatever resources they ask for. Here meeting worker demands is important to us. But this is not likely important for its own sake. Rather, decision-makers probably believe that meeting worker demands will likely build trust between the workers and the system. This in turn will increase the likelihood of their coming to work during times of worker shortages which will allow the health care needs of more people in society to be met. So meeting worker demands is instrumentally important for meeting the health care needs of as many people in society as possible. This in turn is instrumentally important for saving as many lives as possible and increasing the overall health of the community. An intrinsic value, on the other hand, is something important for its own sake. The higher in the chain just described that you go, the more intrinsically valuable the consideration becomes.

Another way to look at this is to reverse the links. That is, if the peace, security and well-being of all humanity were one's values – what was most considered most important in life, then what considerations would be important in order to achieve these? Likely, the values of tolerance, kindness, sharing of resources would also be important as these would advance the causes of peace, security and well being. And what would be important for increasing the tolerance, kindness and sharing of resources among a pluralistic humanity? Leaning about and coming to genuine understanding about the diversity of the world, developing the knowledge and skills required to overcome barriers to meeting basic needs are two values that would be crucial for this – they are crucially instrumental for achieving the broader values. And how do we build the requisite understanding, knowledge and skills? Having the youth in community stay away from lifestyle choices that impair their health, their ability to think, learn and work, is essential. As is ensuring educational opportunities are pursued aggressively and in the right ways.

### *Some Implications*

There are several important implications to thinking about ethics in this way.

First, on this approach there are not some decisions that are about ethics and others that fall outside the ethics bucket. This goes against the thinking of some who feel that there are clinical questions, finance or economics questions, legal questions, marketing questions and so forth, and then there is a limited collection of issues that have to do with ethics. But on this approach such distinctions are seen as mistaken – as they implicitly privilege certain values and beliefs without first justifying them.

For example, it is not uncommon in the healthcare setting (both clinical and administrative) to find individuals who are struggling with a challenging case (and this is particularly true of my physician colleagues) to be focusing on the question, what are our legal responsibilities? To limit the scope of how a problem should be resolved to how do we meet the legal responsibilities of the parties involved, is to say that the most important, if not exclusively important, consideration in solving the problem is obeying the law. And while this is of course an important consideration, there are at least two problems with it.

On the one hand there are likely many other considerations that are at least as important (such as serving the needs of those in our care to the best of our ability, understanding what a meaningful life looks like for those in our care and making decisions that are consistent with their values and beliefs, understanding our own values and beliefs and making decisions that allow us to live with integrity) that our decisions should take into account. On the other hand, there may be limitations with the directions provided by the law (such as requirements for action that are too bare, that are contested – seen as unethical by some, and that simply do not fit in the context of the situation itself). So on this approach there is no tidy ethics bucket. Rather, we want to ask of any decision, action, or attitude, is it based on justified values and beliefs?

Second, there is no binary answer to the question is a given decision justified? The answer will not simply be yes or no. Rather, there is a gradient along which the justification of a given decision, action or attitude will fall. To the extent that a decision is based on well considered values and beliefs, it falls closer to the justified end of the spectrum. To the extent that it is not, it will fall closer to the unjustified pole.

Third, ethics here is about both content and process. We usually think about ethics as the umbrella under which right action resides. In other words, we often think of ethics as describing the content of what the right answer to a question is. So you might hear someone say, I know it's not ethical, but I'm going to do it anyway. The speaker here thinks that ethics just describes those actions, which some special authority demands. But on the approach recommended here, ethics is about the process by which decisions are made as well as the description of what right action looks like.

So ethics involves the critical examination of the values and beliefs that underpin our behaviours and reflection on the values and beliefs that should guide our behaviours.

### ***Why Bother With This Ethics Stuff?***

All this seems like a lot of work, including some very taxing mental gymnastics. Life is both busy and short. Why should we spend time and energy thinking about this ethics stuff?

There are at least two general reasons why reflecting on our behaviours in this way is valuable.

Taking the time to examine what we think is true about the world and what we should hold important will likely lead to making decisions, taking actions and having attitudes that are more consistent with our respective views of the world. This is important because living with integrity is likely very important to all of us. Indeed, not living with integrity can have dramatic impacts on our health, broadly defined, and on the quality of our lives. And thinking carefully about our values and beliefs and making decisions accordingly can help us to live with greater integrity.

Think of it this way, if living with integrity requires walking our talk. And if we haven't undertaken the critically reflective work of what our talk is, then how can we possibly know what our walk should be?

The benefits of ethics analysis when it comes to system-level decision-making in health care are even greater. These will be discussed in an upcoming section.

## System-level Decision-Making in Health Care

### *Health Care*

Health care touches almost all aspects of our lives and is obviously very important to all Canadians. The reasons for this are various. It is a means for staying healthy and helping us to flourish in our lives. It can help us to deal with trauma and unexpected illness. It can help us to cope with chronic disease and suffering. It can provide support in almost all aspects of our lives in our later years. It can help us to deal with death and the dying process. It can help us to grieve and live through loss. For many of us, it is a way to express our concern for others and to exercise our competencies. For some of us it provides an avenue for spending our time meaningfully as volunteers, and for many others it provides employment.

As this "industry" is not about producing widgets, but rather about engaging in a collective enterprise to help people live better lives, the decisions made in this setting are very important. They have implications for all members of society, from patients and their families, to clinical, administrative and all other staff, to those few who aren't directly affected but who might one day be and whose tax dollars help support the system and who live in the community that is affected by the decisions.

### *System-Level Decisions*

Decision-making in health care can be divided into those that are about particular patients (such as what the goals of care for a given patient are and what interventions might be appropriate for achieving these goals) and those that are about the system. System-level decisions refer to almost any decision that impacts a group of people, either by establishing rules of conduct (e.g. non smoking policies), determining what and how resources will be allocated (e.g. program and service prioritization), or offering guidance for how decisions should be made or care delivered (e.g. attempted resuscitation guidelines).

### *Who Makes System-level Decisions*

Almost anyone who has an administrative role in the health system is involved with making system-level decisions. Beginning at the most obvious places, those who are involved with setting the direction of the system in general or of a particular area or program are making system-level decisions. Those involved with making decisions about what resources will be available and how these will be used are making system-level decisions. Those providing direction for how staff should behave or relate to one another and the people they support are making system-level decisions, even if these do not get codified into a policy or even written down anywhere.

## Ethics and System Level System-level Decision-Making in Health Care

### *Ethics-Related Challenges of System-level Decisions in Health Care*

Examining personal decisions in everyday life through an ethics lens can be challenging. This challenge becomes more difficult in a healthcare context, harder when focusing on system-level decisions, even harder in a public healthcare context, harder still in the context of a public healthcare system in a democratic society, and even more difficult when this system exists in a richly multicultural society.

In other words, the nature of the Canadian health system introduces a number of complexities that will need to inform any thinking about the values and beliefs that should guide system-level decisions made therein.

The first complexity, as alluded to earlier, is that when it comes to making health care decisions, there is usually a great deal at stake – for those affected by the decision, those making the decision, and those indirectly affected. So the stakes are usually very high when it comes to health care decisions. Like a high stakes gambler, it is easy for those operating at a high altitude of decision-making to get accustomed to high stakes such that they no longer seem daunting. In the face of a billion dollar budget, a decision involving a few million dollars doesn't seem a big deal. But the beds that money will open will have an impact on a number of people – managers, care providers, patients and their families. The implication of this is that the imperative to use the tools of ethics in making and reviewing decisions in this context is great.

Second, as mentioned earlier, we often lack a shared language for addressing the ethical dimension of the decisions we face. We feel these tensions at a gut level, know that they are important and have something to do with ethics, but, with the pressures of a multi-disciplinary, hierarchical, high-tension, fast-paced world of health care, it is difficult to find the words to productively engage each other in discussion about the issue. Even more problematic is that for many of us this ethics dimension remains hidden such that we don't even recognize that the questions and issues we are grappling with have an important ethics dimension – they are based on values and beliefs. This calls for all of us to work harder at learning and using a shared ethics language to discuss the issues and questions that we face.

Third, we live in a democratic context. Interpreted richly, this entails that everyone affected by a decision ought to have a way of being heard in the deliberation about how it is made.

Fourth, we live in a multicultural setting. And while this diversity is certainly one of the strengths of this country, the fact is that when it comes to determining what values and beliefs ought to govern system-level decisions, a clear consensus will not be likely.

Bioethics theory has not been able to provide it. Principles don't work because... Virtue theory doesn't work because...Need a procedure based approach because...

And fifth, the shift in Canadian Health Care to regionalization notwithstanding, the health system is not really a coherent, coordinated system at all – but rather a complex of different programs and institutions that try to coordinate their activities. And each of these programs and institutions have a fair degree of specialization such that the beliefs involved with the system-level decisions made therein are complicated bits of knowledge that requires the expert specialist input.

### ***Four Ethics Dimensions of System Level System-level Decision-Making***

In light of the above complexity, we can articulate four important aspects of any system-level decision that deserve special attention from an ethics perspective: 1) the relationship among the decision-makers and the integrity of the decision process itself, 2) the nature of the public engagement that informs the process, 3) the nature of the staff consultation that informs the process, and 4) attention to those affected by the decision, including support for those who may be placed in ethical difficulty as a result of the decision.

### ***1. Modeling Ideal Communication and Making Ethics Explicit***

If you accept that all our decisions, attitudes and actions are based on beliefs and values – or considerations that we take to be important – then it follows that the very way that system-level decisions are addressed is also based on beliefs and values. And we can ask, is this approach itself justified? That is, it is based on the right values and beliefs, all things considered?

For example, a common challenge faced by decision-teams is that the members disagree on various issues. Usually when this happens, decisions are made by the last, loudest, or most powerful voice at the table. But these voices may not reflect values that can stand up to close scrutiny. Reflecting on the process of how decisions are made means asking, if there is disagreement among those on the decision team, how will the disagreement be resolved? The answer will depend on considerations of what is important. If such things as coming to agreement if possible, genuinely respecting and responding to all different perspectives, and hearing and considering a variety of viewpoints are important considerations to the team (considerations the team values – or the team's process values), then the team will likely adopt a consensus model of decision-making. If, on the other hand, making a decision quickly, not wasting time, and acknowledging the legitimacy of a given hierarchy are the team's values, then brief discussion followed by a vote or decision by the most powerful group member will be the model used.

Other questions we want to ask of the process of decision-making include: Why is this issue being raised? What problem is being addressed? Is this to be a decision, policy or guideline? What is the rationale for this choice? Who is leading the decision team? Who is on the decision team? How will the members of the decision team relate to one another? What kinds of reasons will count as good ones? What standards of evidence will be required before information is accepted as fact? Who is the decision team accountable to? Who is the decision team responsible to?

Some of the values that are appropriate for informing team decision-making processes include: integrity, inclusiveness, timeliness, consensus, creating moral space and time, transparency, intellectual honesty, respect for professional integrity, unconditional positive regard, and empathetic understanding.

There are of course many models of decision-making that are nuanced variations of the above. But whatever model chosen, it is important to ask how it is justified – is it based on the right values and beliefs?

What outcomes?

As the group engages its work, it will have to be clear on its authority to make decisions. In other words, as different issues are tackled, what will be the status of any decisions made? Will they be binding?

Who speaks?

An important question the group will have to determine is who will get a voice at the table. That is, often having a space at a decision table is not enough to have one's perspective meaningfully heard. This is especially true in the hierarchical culture of health care where decision authority rather than richness and importance of perspective are the determinant of who is heard.

What's open for discussion?

How narrow must the conversation be? Must it remain limited to the predefined issue in question, or can that be revisited?

What types of reasons count?

Are there any boundaries to the types of reasons that are offered in the discussion? Can strongly held religious views be used to articulate and defend certain values?

How is difference dealt with?

Any question that is worth struggling with often has at least two legitimate perspectives. What will the group's attitude be towards different, and sometimes difficult to hear and unpopular perspectives on issues? Will this difference be actively sought out and meaningfully engaged? Or will it be silenced in effort to get decisions made and not rock the boat?

How are decisions made?

When an issue is being dealt with, how will a conclusion be reached? Will the most powerful member of the group take the conversation under advisement and make the decision himself? Will the group vote on the issue? Will the group struggle until a consensus is reached? Will the perspective of the person with the most stamina or loudest voice be the last to be heard and carry the day?

What standards will be used to decide what counts as evidence?

As we saw, beliefs are one of the two main factors in decision-making and ethically justified decisions rest on the best available facts at the time. The challenge is that we have different standards of evidence for what counts as a fact. Is it enough that we have anecdotal evidence from what we consider to be reliable sources? Do we require a degree of scientific rigour? What is this standard?

The issues that system-leaders choose to focus on, the processes that they use to make these decisions, the values that are at stake in these decisions, the value trade-offs that are made, and the justification for this balancing – all of these aspects of system-level decisions are based on an understanding of what is important. The first ethically important dimension of system-level decision-making in health care is the actual recognition of these aspects as value-laden, and making the rationale behind the value choices made transparent.

## 2. Public Engagement Strategies

We often take for granted that we live in a democracy. But what does this actually mean? For one thing, it suggests that we take the value of self-determination very seriously. That is, if a decision impacts me, I should have a say in it – in some proportion to the extent of that impact and relative to the impact it has on others. In the context of much public policy, this means that when decisions that affect the community are made, some form of community consultation is solicited. If a new building is being developed, if roads or infrastructure is being constructed, the community is either directly consulted through such vehicles as public meetings or town halls, or given the opportunity to provide feedback.

As we saw in an earlier section, when it comes to health care, the system-level decisions we make have an enormous impact on individual members of the community and the community at large. Yet there is almost no community consultation involved with most of our system-level decision-making in health care. Some would suggest that this failure to engage the community in the decision-making ignores a crucially important value and therefore diminishes the ethical justifiability of these decisions. This resource takes seriously this concern and argues that decision-makers need to think carefully about community consultation in their decision-making process.

The challenge with community consultation in health system decision-making is that we are not used to thinking about this question in any rigorous way. The fact that it is so complicated, raising questions of appropriate representation, the extent of citizen involvement, how to handle interest groups, and what to do in the face of disagreement does not help. Another challenge that faces decision-makers is that even after it is agreed that some form of consultation is required, the knowledge and skills to undertake the consultation is lacking.

Notwithstanding these challenges, if system-level decision-makers are to make democratically legitimate decisions as required for ethically legitimate decision-making, then they have a responsibility to take this seriously and begin moving forward on this agenda.

The types of questions to be engaged that will have to be addressed include: Who will be affected by the decision, and to what extent? Is there a way to articulate and understand some of these perspectives from within the decision team? If the decision is to have a wide impact, from what groups of people should some feedback be solicited? What is the best way to solicit this feedback? If a consultation is considered, what work is the meeting to do? Who should participate in the consultation? What education about the issue will be provided to participants? How will this education be provided to minimize bias? How will the discussion be structured? How often will participants meet? How will what the participants have at stake in the conversation be accounted for? What decision-making authority the group will have? At what stage of the decision-making process will the group convene? How should these individuals be recruited? How and from whom will this specialized information be solicited?

Direction on these and other questions are offered in a section on developing a public participation framework found later in this workbook. Here the point is just to identify this as a key ethical dimension of system-level decision-making.

### *4. Education, Communication, Downstream Support, Sustainability, and Evaluation*

By definition, system-level decisions impact groups of people who themselves must make decisions downstream in response to the upstream system decision. Sometimes, indeed often in the setting we are concerned with, system-level decisions make life challenging for those impacted. Accordingly, those working upstream have an important duty to anticipate the difficult positions those working downstream in the system will face as a result of the decision and a) do what is possible to minimize this impact, and b) seek to ensure support is available to these folks to help them deal with the difficulties they will now face.

For example, a decision at the regional level to limit access to ventilated beds only to certain types of patients will leave the physicians and staff working for the region who must decide which of their patients best fit that criteria and then what to do with those that do not – when all of them might likely benefit from the resource. In this example, the clearer the rationale offered at the regional level about why the decision is made and the better processes in place for appealing the policy, the more likely it will be that those affected will be able to live with it. In addition, the regional decision-makers might provide training in bedside resource allocation decision-making to those impacted to help support those impacted.

## ***How the Four Dimensions Relate to One Another***

That our decisions are based on both process and substantive values is inescapable. Whatever decisions we all face, whether personal or professional, individual or at the system-level, we all have processes we use to come to decisions and our decisions are eventually based on considerations of what is substantively important. Moving towards ethically justified decisions in the health system context requires paying attention to all four of these dimensions.

Dimensions one and three are closely linked. That is, how the decision will be made involves thinking both about the process the team itself will follow and the consultation process that the team includes. Accordingly, those leading the team should think carefully at the beginning of any decision process about these questions and facilitate a conversation about these questions with the team even at the first meeting.

Once the procedural values are clear, the work of the process should move on to trying to figure out the facts of the situation, what substantive values the decision taken should be based on, what the different options are for responding the question at hand, and which option best responds to these considerations. An important substantive value is helping people to live with integrity. This value should be articulated and the options considered should respond to it.

Finally, whatever decision is settled on, those affected by it should be identified and ways of supporting these individuals should be incorporated into the solution plan.

## ***Tell Me Again, Why Ethics?***

Again, the assumption here is that all system-level decisions are motivated by and based on values, whether these are made explicit or not. There are a variety of reasons why critically engaging these values and beliefs is important.

First, decisions/policies that are more ethically transparent tend to be based on morally justifiable rationale (the more views a given decision/policy is exposed to and is able to withstand, the more reason one has to feel the policy/decision is justified).

Second, explicit attention to core values leads to policies more consistent with organizational values.

Third, identifying core values can inform a framework for assessing any strategy/action item from an ethics perspective.

Fourth, being clear about the values at stake in a policy decision can help identify values tensions, which in turn can provide the organization and the community it serves an opportunity to openly struggle with these tensions and thereby move forward in its own ethical development.

And fifth, being explicit about core values leads to potentially greater compliance and less moral distress (care providers may be more likely to accept and feel better about proposed changes to practice delivery if they have access to and understand the rationale behind the decision for the change.)

## Part Two: Things to Do

In this section of the book we move from the conceptual to the practical. Here we will consider specific action items that leaders and organizations should take if they have the first half of this text convincing. This part will also describe frameworks and processes that can aid decision leaders to operationalize the values advocated earlier. And it will provide worksheets and other support materials to further assist leaders in living out these commitments.

## Organizational Commitments

Living with integrity does not just happen. It requires intentional action and hard work. The first step in this direction requires making a commitment to acting in certain ways. If you have found the arguments above persuasive, including the importance of attending to the four ethically salient dimensions of system-level decision-making described above, then there are five key commitments that organizations, led by their leaders, should make. These commitments will need to be accompanied by strategies and procedures to ensure they are actually lived out in the organization.

### *Commitment 1: Develop A Shared Language For Discussing Ethics Dimension Of Issues And Make The Values Dimension Of Decisions*

Leaders and organizations will have to make it their formal intention to find a common way of talking about the ethics dimension of their work. They will also have to make it an expectation that the values that ground the decisions they make will be made explicit, along with the values traded off in the decision and the rationale for this balancing.

### *Commitment 2: Develop a Public Engagement Philosophy and Strategy*

Public engagement can take many forms, including a variety of different actors, with different objectives. Without intentional action, public engagement efforts will be ad hoc with very different levels of actual input into the decision-process. To really honour the importance of meaningful citizen engagement into the system-level decision process, leaders and organizations will have to make a formal commitment to this. The commitment cannot be a general one, but should be to a specific understanding of the meaning and relevance of public engagement within system-level decision-making in health care.

### *Commitment 3: Value the Ways Teams Work Together to Make Decisions & Seek to Model Ideal Communication*

The third commitment that leaders need to make in order to live out the five ethical dimensions of system-level decisions is to treating each other with respect and ensuring that decisions are based on reasons and not on things like power dynamics (the use of coercion, manipulation, or deception), inappropriate group dynamics, and the like. This involves examining the legitimacy and mandate of decision-makers, and the relationships between them. It requires explicitly and intentionally attending to what and how reasons are traded in the decision process.

## Ethics-Based System-Level Decisions: Towards the Ideal

The world is not ideal. But in spite of this rather significant fact, it can be illustrative to imagine what system-level decision-making in an ideal world might look like. Describing one's perspective of the ideal helps us to critically reflect on what actually would be ideal. And to the extent that the picture itself is well-justified, it will point out what we should be striving for.

As indicated earlier, I suggest that in the ideal world, leaders and organizations will have a clear understanding of the evaluative nature of their decisions, and they will be comfortable exposing their decisions to great scrutiny. Moreover, a systematic infrastructure for public engagement and staff engagement will be in place, where the values of the community will meaningfully emerge and be tied into all aspects of decision-making, from the very setting of the decision agenda through to the decision-making and implementation plan.

Because this ideal is so radically different from today's world, it is difficult to imagine exactly how decisions in this context might get made. Moreover, because ideally the process itself would be shaped by those impacted by it – the community – envisioning it may be beyond imagination.

In what follows I offer what might be a glimpse into the ideal decision process. My sense is that this would actually pale in comparison to the richness of decision-making in the ideal. Nevertheless, I think the processes described would significantly advance the justification of decisions arrived at through it as compared to the way system-level decisions are made in current times.

### *Decision Frameworks, Trees, and Processes*

The language of frameworks and processes is confusing. Sometimes the terms are used to point to methods of decision making, while at other times the same terms are used to describe a set of values or principles.

In this workbook, by decision framework, I mean the overall philosophy, method, and series of steps over time that are required for the making of a system-level decision. The decision framework I recommend below includes multiple phases that begins at the point the issue to be addressed is identified and ends with the implementation of a comprehensive downstream support and sustainability plan. The decision framework describes in detail the comprehensive series of steps over time that a decision will have to be made through to achieve maximal justification.

I use the term decision tree to point to a summary of the decision framework. This encapsulation of the multiple phases of the decision framework into one document captures at a glance what needs to happen for a decision to be justified, while still providing practical direction for how to tackle a specific issue or question in a short time frame (60 to 120 minutes) in a systematic manner that pays explicit attention to the value dimensions of the issue in question.

### *Decision Framework*

The decision framework I recommend in effort to live up to the five ethically significant dimensions of system-level decisions, and the use of which I suggest will offer the greatest chance for justified decisions involves a number of different phases.

In Phase 1 of the decision process, the issue that is being struggled with is identified and the core team responsible for resolving the issue or making a decision or recommendation is assembled. The team may be preexisting, such as an executive committee, or it may be put together ad hoc, such as a group developing policy for pandemic planning. At this stage, the decision team seeks to develop a clear picture of the question(s) it is meant to answer, its mandate, the values that will govern the relationships of the team members, and the process it will use for generating the policy solution. This phase is important for living up to the values of transparency and reason-driven (as opposed to power-driven) policy-making. It is in this phase that the first ethics dimension of system-level decisions should ideally be addressed: how individuals and teams responsible for planning, implementing, and evaluating programs actually make decisions.

It is recommended that at the outset of their relationship it is important for teams to explicitly tackle how they will operate and treat each other as they engage their work – specifically answering the above questions. Key values that should guide these decisions include trust, honesty, humility, sincerity, meaningfully treating others with respect, equality, basing decisions on reason and not power, coercion, or manipulation.

Phase 2 of the decision process is a pre-deliberative individual reflective exercise to be undertaken by the members of the decision team respectively. Here the individuals are asked to use a systematic process to reflect on their own perspectives of a) what the key question being asked in the issue is, b) what the context looks like, what operating beliefs are correct, what information is missing, and so forth, c) what is important in resolving the issue, and d) what solutions seem most appropriate.

To facilitate the work in this phase, a homework package for the issue in question is sent out to the members of the group. This provides members the opportunity to begin to reflect on the beliefs and values that inform the issue from their perspective. The pre-work can either be submitted to the group's secretariat in advance of the meeting for collation and presentation at the meeting, or members can simply be asked to come prepared to share their reflections during the conversation at the meeting.

The purpose of this phase is to assist team members to identify their own biases, recognize the limitations of their own perspectives, and begin creating the space for reflective deliberation about the issue at hand. This phase of the process is also intended to lay bare the evaluative aspects of the decision process and to contribute to the possibility of a reason-driven solution to the question at hand.

In Phase 3 the team comes together to engage in a deliberative discussion. The group follows a systematic process with a view to coming up with an initial position on the issue in question. The systematic process is the same as in the pre-deliberative individual exercise: the group comes to terms with the specific questions to be answered, generates a shared understanding of the context, including areas of disagreement and insufficient information, identifies the most important considerations or decision criteria (code for values) by which solutions should be judged, brainstorms different options, systematically evaluates these, and settles on a preliminary decision. The decision is articulated, with the value trade offs and the justification for the balancing made explicit.

This meeting would ideally be facilitated in order to keep members' focus on the question at hand and to manage time to ensure the group get through the process within the time allotted.

In Phase 4, the decision team develops a consultation plan. After coming up with a preliminary decision, the group would convene again to discuss what other perspectives and voices ought to inform the decision process. This is perhaps the most important and yet weakest link in the decision framework. It is the most important because it is where the values of democratic legitimacy and health care professional integrity are honoured. Yet it is the weakest because there is no infrastructure to support meaningful public engagement in the policy process, and little infrastructure to support staff engagement. Critical to the ability to carry out this step will be the development of public and staff engagement philosophies and strategies on the part of the organization. Accordingly, this and the next phase of the framework may be given short shrift. Nevertheless, having these phases articulated as part of the framework both names the importance of them and provides the opportunity to decision leaders to capitalize on whatever room for meaningful engagement there is within the organizational structure.

It is imperative to be clear that absent this phase of the framework, any system-level decisions will of limited justification, particularly from the perspectives of democratic legitimacy and respect for professional integrity.

Phase 5 involves the undertaking of the consultation plan developed in Phase 4.

Phase 6 involves having the decision team arrive at a final decision or recommendation, this time having gained insight into the decision from the consultation process. Once the participation of appropriate outside individuals and groups has been completed, in this phase the group reconvenes to deliberate towards final decision on the issue at hand. This decision may actually complete the process, or, depending upon the feedback, it might result in the re-initiation of the process, taking into account the questions and concerns raised by relevant groups.

In this phase, the group would go through the same steps as in phase 3. That is, based on the feedback they have received, they would confirm the specific questions to be answered, revisit their collective understanding of the context, including areas of disagreement and insufficient information, accept the most important considerations or decision criteria (code for values) by which solutions should be judged, brainstorm different options, systematically evaluates these, and settle on a final policy decision. The decision is articulated, with the value trade offs and the justification for the balancing made explicit.

Phase 7 then involves developing a downstream communication, education, support and sustainability plan. At this point, the group has already come to a decision on the issue in question. In this phase the group meets to consider who needs to know about the decision in question, what education will be required by those affected as a result of the decision, and what supports might be provided to those who may be compromised by the decision in question. It addresses questions of evaluation and sustainability.

In Phase 8, the downstream communication, education, support and sustainability plan developed in Phase 7 is implemented.

The framework is summarized in the following decision tree.

### *Decision Tree – For Individuals and Teams Addressing System Level Issues*

All decisions made by individuals or teams are based on values in that they seek to achieve something that is important. Ethics is about ensuring that what is considered important is made explicit and well justified – here justified means that the decision is based on reasons that have been made explicit and rigorously tested against competing perspectives. The more serious the issue being dealt with, the more important it is that the decision be made using such a process.

Note: the process looks linear, but in application there will likely be some jumping around. For example, it will be important to regularly check in to ensure that the right question is being asked. As well, the importance of various values and questions about missing information will likely surface throughout. Users should simply try to be as rigorous as is reasonable in using the process and to ensure all the steps are attended to.

| | Description | Elaboration | Tips |
|---|---|---|---|
| 1 | Agree on the question being asked. | The question we ask will determine the type and scope of answer we get. Here the task is to ensure that the group is working on the same problem and asking the right question that will help solve that problem.<br>Issues are often complex and this step involves clarifying exactly what work is being done by the policy.<br>While there will be many questions that present themselves, the challenge here will be to come to a shared understanding of which of the many questions should be addressed using this process. | Design your question so that it allows for a variety of possible answers, not just yes or no.<br>Questions that begin with what or how work well.<br>Only include descriptors about which there is explicitly shared agreement in your question ("where should we place Mrs. C?" instead of "how do we get Mrs. C into a long-term care facility?")<br>Pose your question in neutral terms ("how should the region allocate resources", as opposed to "how can the region not waste resources on the elderly")<br>Focus on the broad question which, if |

| | | | |
|---|---|---|---|
| | | | answered well, will likely include the more specific one and will provide meaningful direction for moving forward ("what are the goals of care for Mrs. C?" instead of "What does Mrs. C want?") |
| 2 | Confirm the authority of and working relationships between the decision team | Here the team should confirm what authority it has in the decision process. Is it going to make a decision? Is it to make a recommendation to another group for decision? Is it to make process recommendations for how the issue should be addressed?<br>The team also needs to consider how members will relate to one another. Who will facilitate the discussion? How will respectful treatment be ensured? | The group may wish to explicitly answer the following questions:<br>What is the mandate of the group? Will decisions made be binding?<br>How will airtime in the meeting be distributed? Will all perspectives be counted as equal?<br>What will the group's attitude be towards different, and sometimes difficult to hear and unpopular perspectives on issues?<br>How will a conclusion be reached? By vote? Consensus?<br>What standards will be used to decide what counts as evidence? |
| 3 | Identify the constraints/assumptions/ facts that make up the context. | Here the idea is to ensure everyone is working with the same understanding of the context<br>Those facts are contentious or unclear should be made explicit with points of agreement and tension named.<br>The goal is to ensure a shared understanding of the situation, including areas that may be unsettled or controversial, against which the decision is being made.<br>The quality of a fact will depend on the evidence we have to support it. For the facts that are listed, explore what reasons people have for their beliefs. | Work hard to ensure that what gets listed here are facts (things that are true or false) about the world and not values (what is important to us).<br>Facts usually involve declarative sentences with some form of the verb to be.<br>As many facts make up any context, remember that the goal is simply to ensure that the team making the decision is on the same page, looking at the same picture<br>List only those about which it is likely to be important that everyone agree, including things that may be contentious and relevant ("Mrs. C would have wanted to live at home as long as possible" and "The waiting list for Eden Vale Home is three months"; not necessarily "We have a publicly funded health system" |
| 4 | Identify the values that should guide the answer. | This step is where values are made explicit<br>It involves brainstorming what is important in answering the question.<br>The values become the criteria by which the various possible solutions to the question can be judged.<br>At this point all important considerations should be named and listed, regardless of degree of importance. | Try to use complete sentences in completing this step. Do this by answering the question, "whatever solution we come to in the situation, it is important that the solution…"<br>Values can be instrumental (important because they give us something of greater importance to us) or intrinsic (important for their own sake). When a consideration is identified as important, explore whether it is important for its own sake or because it gives us something else of importance.<br>If the latter, be sure to capture the intrinsic value on the list. |
| 5 | Of the values listed, identify which are | This step is where the criteria brainstormed are prioritized, so that the most important considerations (values) that should guide the solution chosen. | Assign each item a numerical value reflecting its relative importance (e.g. 5=crucial, 1=important). |

| | | | |
|---|---|---|---|
| | most important. | The resulting list will be the criteria against which the quality of different options will be judged. | |
| 6 | Brainstorm options for answering the question. | At this stage different alternatives for answering the question should be entertained.<br>This step is aimed at creating the room for creatively exploring what kinds of things, conventional or not, might meet the criteria indicated and solve the problem.<br>Options should just be listed and not judged. Just because an option is named at this stage does not mean that it will be followed up. | Have the discussion leader explain the brainstorming exercise<br>Invite members to provide possible ways of answering the question<br>If anyone challenges an option or offers critical feedback, acknowledge it but don't engage it and ask that this evaluation be held until the next step |
| 7 | Analyze each option against the values. | This step requires looking at the possible solutions to see which ones best live up to the considerations that are seen as most important.<br>This should be done systematically, checking each of the reasonable/viable options against each of the most important criteria. | Put the list of prioritized values next to the list of possible options (flipcharts are helpful for this).<br>Then pick an option and go through each of the prioritized values asking, "How well does this option live up to this value?" |
| 8 | Make a preliminary decision, detailing the best option and articulating the justification for the decision. | Based on the above process, some amalgamation of options will likely surface as best meeting what is considered most important.<br>At this stage the goal is to choose a solution to respond to the question.<br>Once a choose has been articulated in detail, spell out what values the choice lives up to, what important considerations the choice does not honour, and how this balancing is justified. | The solution need not be one or other of the options, but may be a collection of different parts from a few options. |
| 9 | Check decision against core values. | Here the choice is to be checked against the core values of the team, unit, or organization. Where these have not yet been articulated, other values from the literature may be used instead.<br>Successful meeting of these core values is a sign of a good answer.<br>Failure to live up to core values is a sign that more work may need to be done in the above steps. | As in Step 6, put the list of core values next to the list of possible options (flipcharts are helpful for this).<br>Then ask of the chosen solution, "How well does this option live up to this value?"<br>Specific questions to ask include, how well does the decision…<br>Minimize societal disruption<br>Recognize and support the post-pandemic work-environment<br>Honour the duty to provide care and services in the case of a pandemic that healthcare providers and staff have<br>Honour reciprocal duties on the part of the system and society towards care providers<br>Safeguard the physical and mental well-being of staff<br>Help staff make informed decisions<br>Help staff do the right thing – make decisions that are ethically sound |

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| | | | Provide health care staff and organizations access to the appropriate knowledge and tools to help deal with the ethical dilemmas that they may face<br>Address the concerns of healthcare workers over their family safety<br>Consider what community supports might be needed for healthcare providers<br>Utilize decision processes that are based on sound ethical principles (including attention to transparency, appropriate consultations, etc.)<br>Meet the health care needs of the community.<br>Ensure that staff working outside their scope of practice are competent to do<br>Minimize the risk of harm to other individuals waiting for care unrelated to pandemic<br>Fairly distribute the responsibility to look after caring for the community<br>Involve open, frank communication with healthcare workers<br>Is transparent with the public about the effect of human resource policy on health care delivery<br>Recognize the role of public input into policy decision-making |
| 10 | Develop a plan for consulting with relevant others. | These steps reflect that good answers and legitimate answers both require the participation of those affected in the decision process.<br>In addition, inclusiveness in process is crucial to the successful implementation of almost any decision – made at the individual or system level.<br>These can be the most challenging steps in the process, but are indispensable for achieving justifiable policy solutions. | Brainstorm who is impacted by the decision<br>Consider what level of engagement with each group will be required to ensure the decision is *as wise* as it should be<br>Consider what level of engagement with each group will be required to ensure the decision is *as legitimate* as it should be<br>Consider what level of engagement with each group will be required to ensure the decision will be followed<br>Develop strategies and assign responsibilities, resources and timelines for completion of they consultation process. |
| 11 | Conduct consultations. | | |
| 12 | Review preliminary decision based on consultation feedback. | At this stage the goal is to reconsider the facts, values, options, and analysis that led to the initial position based on feedback from the consultations. | Depending on the feedback received, ask:<br>Did we get the facts right or is something different?<br>Do we have the values prioritized right, or do we need to change the list in any way?<br>Are there more viable options than we actually considered?<br>Is there an option that is more appropriate in light of the revisions we have made? |
| 13 | Make a final decision. | The above process may yield a different solution. The goal at this stage is to confirm and describe the solution, and its justification, in detail. | Write out:<br>The question:_______________<br>Our solution is to:___________<br>This lives up to the values of:__ |

| | | | |
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| | | | This sacrifices the values of:___<br>This is justified because:___ |
| 14 | Develop an implementation, communication, education, downstream support and sustainability plan. | Policy decisions don't end with a content decision. Others will need to know about the policy, others will have to carry it out, and others will be affected by it. Moreover, as the situation changes, the policy itself may need to be monitored and evolved.<br>Plans need to be put into place to ensure that a) those that need to know about it are told, b) those that will be affected by it and need to carry it out are appropriately educated, c) resources are in place to support those who might be compromised by it, d) avenues for appeal are in place for those that disagree with it, and e) ongoing responsibilities and resources are in place for ongoing monitoring and, where necessary, review. | |
| 15 | Implement decision. | | |
| 2 | Implement communication, education, downstream support and sustainability plan. | | |
| 16 | Live with it and learn from it | This serves to remind that our decisions should be revisited and reevaluated some time later to see whether the decision was made and justified well, or what might have been done differently. | |
| The objective of this process is to arrive at the best decision all things considered (as opposed to any objectively right answer). In other words, should be able to say for any issue that the decision has been arrived at having taken time to carefully consider the facts of the case and what's important from all the key viewpoints – and this has been done with sincerity and integrity. | | | |

The following table illustrates these key steps:

| | | | | | |
|---|---|---|---|---|---|
| Beliefs/facts /missing information | | | | | |
| Key question(s) | | | | | |
| Values | Whatever our solution, it is important that… | Value | Priority (5 = crucial 1 = important) | | |
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| Alternatives | | | | | |
| Evaluation of alternatives against values | | | | | |
| The option we consider most consistent with the most important considerations is | | | | | |
| This option best lives up to the values of | | | | | |
| This option risks not living up to these values | | | | | |
| We believe that on balance this is justified because | | | | | |

## Worksheets for Decision Framework Phases

### *Phase 1 Worksheet: Identification of Issue(s) and Decision-Team Parameters*

| | | |
|---|---|---|
| Group | Name of group. | |
| Issue | What issues is the group to address? | |
| What is the expected outcome of the work? | As the group engages its work, it will have to be clear on its authority to make decisions. In other words, as different issues are tackled, what will be the status of any decisions made? Will they be binding? | |
| Who will speak? | An important question the group will have to determine is who will get a voice at the table. That is, often having a space at a decision table is not enough to have one's perspective meaningfully heard. This is especially true in the hierarchical culture of health care where decision authority rather than richness and importance of perspective can be the determinant of who is heard. | |
| How will difference be dealt with? | Any question that is worth struggling with often has at least two legitimate perspectives. What will the group's attitude be towards different, and sometimes difficult to hear and unpopular perspectives on issues? Will this difference be actively sought out and meaningfully engaged? Or will it be silenced in effort to get decisions made and not rock the boat? | |
| What's open for discussion? | How narrow must the conversation be? Must it remain limited to the predefined issue in question, or can that be revisited? | |
| What types of reasons count? | Are there any boundaries to the types of reasons that are offered in the discussion? Can strongly held religious views be used to articulate and defend certain values? | |
| How are differences to be resolved and decisions made? | When an issue is being dealt with, how will a conclusion be reached? Will the most powerful member of the group take the conversation under advisement and make the decision himself? Will the group vote on the issue? Will the group struggle until a consensus is reached? Will the perspective of the person with the most stamina or loudest voice be the last to be heard and carry the day? | |
| What standards will be used to decide what counts as evidence? | Beliefs are one of the two main factors in decision-making and ethically justified decisions rest on the best available facts at the time. The challenge is that we have different standards of evidence for what counts as a fact. Is it enough that we have anecdotal evidence from what we consider to be reliable sources? Do we require a degree of scientific rigour? What is this standard? | |

## *Phase 2 Worksheets: Pre-Deliberative Individual Reflection*

### ***Sample pre-work package***

To: Members of the influenza pandemic planning group

Date:

Dear Member,

In the most acute phase(s) of an influenza pandemic, there will be a significant shortage of various types of healthcare providers (HCPs). An important question managers in the system will face is, how should HCPs working with/for a region be approached to provide services at such times?

On **date, 2006** the Ethics Pandemic Group will be meeting to develop an initial position on this question.

**Kindly complete the following worksheets and submit them to… by date. There are five worksheets:**

**Worksheet 1**: confirm the question being asked – will answering this question provide the group/organization meaningful direction?

**Worksheet 2:** review the facts/assumptions that form the context of this issue. Are these safe things to assume? Is there anything else that should be added to this list?

**Worksheet 3**: look at list of values that should inform our approach to supporting human resources – is there anything missing?

**Worksheet 4**: what are the possible policy options for dealing with human resource shortages at the height of the pandemic?

**Worksheet 5**: consider, whose input is needed beyond our groups in making this decision? What kind of input is needed from each of these groups respectively? What is the best way of obtaining this input?

### *Phase 2 Pre-Work Worksheet 1*

Confirm the question that is being asked…

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|---|
| Tips:<br>Ask yourself what question, if you had an answer to it, would provide clear, complete and meaningful direction for how to deal with the issue you are facing<br>Avoid questions that lead to yes or no answers, as these tend not to offer rich solutions to complex problems<br>Frame the question as how or what should |
| Example 1:<br>Issue – Vaccine distribution<br>Question: Within the priority groups established by the federal government, how should FH allocate the vaccine? |
| Example 2:<br>Issue- concern that staff on my team won't come to work<br>Question: what approach should I take to our team's staffing policy at the height of the pandemic? |

## *Phase 2 Pre-Work Worksheet 2*

What are the salient facts / assumptions / constraints that make up the context of this question?

| |
|---|
| Tips:<br>Focus on those givens that all would agree on<br>Try to leave out evaluative statements (it is important that… people should…) – as these will be covered in the next step<br>Focus on those statements that include variations on the verb "to be" – i.e. "was", "is" or "will be" statements |
| Example: Vaccine distribution:<br>Federal and provincial plans provide a prioritized list of the groups within society that should receive the vaccine<br>The provincial and federal lists are consistent in terms of groups identified and priorities assigned<br>A vaccine will take six months post-pandemic to arrive; it will arrive in small batches |
| Example: Concern that staff on my team won't come to work:<br>Healthcare providers may face very difficult decisions where they will have to balance meeting competing obligations to themselves, their families, their communities, and the health system.<br>They will face decisions of the following type:<br>A married mother of three works as a nurse at the local hospital. A Pandemic alert has been issued and she is called into work. The following day, she notices her eldest son has become ill with symptoms suggestive of influenza and her husband has also fallen ill. She is called into the hospital again.<br>A woman who is a respiratory tech with much unique skills and expertise is called into the hospital. However, her husband is gravely ill with terminal cancer, expected to live only 4-6 weeks. She's been on compassionate leave, but is needed at the hospital.<br>Health organizations will need to develop a system-level response (policy or guideline) to support managers in dealing with potential staff shortages during a pandemic. |

| Other salient facts/assumptions/constraints/givens that make up the context for determining the appropriate structure for regional programs include that… |
|---|
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| |
| |

| INFORMATION THAT IS MISSING … | Is this information available or will it remain unknown? |
|---|---|
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### *Phase 2 Pre-Work Worksheet 3*

What are the criteria we should use to judge the options?
(Answer in the following way…It is important that the decision…)

What is the relevant importance of these criteria?

| |
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| Tips:<br>Focus on what is important at the decision-making (your) level<br>Focus on evaluative statements (it is important that… people should…)<br>Be as specific as possible<br>Include all of the important considerations on the list<br>Try to avoid duplication |
| Example: Vaccine distribution:<br>Support and minimize moral distress of those who will have to make these difficult decisions at the time of the pandemic<br>Declare conflict of interests among decision-makers<br>Follow national and provincial guidelines<br>Maintain the trust of each constituent group<br>Treat all people equitably (everyone gets in proportion to their need) |
| Example: Concern that staff on my team won't come to work:<br>Support team members in making hard decisions<br>Honour the various commitments that team members have to live up to as human beings<br>Maximize the availability of staff when the need is greatest<br>Discharge our professional duties |

| IT IS IMPORTANT THAT… | WHY IS THIS IMPORTANT TO YOU? | PRIORITY SETTING<br>1 = Crucial<br>2 = very, very important<br>3 = very important<br>4 = important |
|---|---|---|
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*Phase 2 Pre-Work Worksheet 4*

What are the possible ways of answering the question?

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|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

1.

2.

3.

4.

5.

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8.

9.

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11.

*Phase 2 Pre-Work Worksheet 5*

Who else needs to be consulted?

The decision about the most appropriate way of handling human resource issues will be based on a perspective including assumptions about the context and what is important. What other individuals and groups should be asked to share their perspectives on the issue? What is the level of engagement required with the group? What is the best mechanism for receiving this input?

| Group to be consulted | Specific purpose of consultation | How should consultation be conducted? | Priority of consultation |
|---|---|---|---|
| Union leaders | | | |
| Emergency Room Physicians | | | |
| Emergency Room Nurses & Allied Staff | | | |
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## *Phase 3 Worksheets: Deliberation Towards a Preliminary Decision*

The agenda for the meeting would follow the questions asked in worksheets 1-4. The agenda would be as follows:

| Meeting agenda | | |
|---|---|---|
| Step | Description | Time |
| 1 | Agree on the question being asked. | |
| 2 | What are the constraints/assumptions/facts that make up the context? | |
| 3 | What are the important considerations that should guide the answer? | |
| 4 | Of these, which are most important? | |
| 5 | Brainstorm options for answering the question. | |
| 6 | Analyze options against the values. | |
| 7 | Make a decision (This may be preliminary or final, depending on consultation that still needs to be done.) | |
| 8 | Check decision against core values. | |
| **The objective of this process is to arrive at the best decision all things considered** (as opposed to any objectively right answer). In other words, should be able to say for any issue that the decision has been arrived at having taken time to carefully consider the facts of the case and what's important from all the key viewpoints – and this has been done with sincerity and integrity. | | |

## Phase 3 Worksheets Step 1

Confirm the question that is being asked…

| |
|---|
| Tips:<br>Ask yourself what question, if you had an answer to it, would provide clear, complete and meaningful direction for how to deal with the issue you are facing<br>Avoid questions that lead to yes or no answers, as these tend not to offer rich solutions to complex problems<br>Frame the question as how or what should |
| Example 1:<br>Issue – Vaccine distribution<br>Question: Within the priority groups established by the federal government, how should FH allocate the vaccine? |
| Example 2:<br>Issue- concern that staff on my team won't come to work<br>Question: what approach should I take to our team's staffing policy at the height of the pandemic? |

## Phase 3 Worksheets Step 2

What are the salient facts / assumptions / constraints that make up the context of this question?

| |
|---|
| Tips:<br>Focus on those givens that all would agree on<br>Try to leave out evaluative statements (it is important that… people should…) – as these will be covered in the next step<br>Focus on those statements that include variations on the verb "to be" – i.e. "was", "is" or "will be" statements |
| Example: Vaccine distribution:<br>Federal and provincial plans provide a prioritized list of the groups within society that should receive the vaccine<br>The provincial and federal lists are consistent in terms of groups identified and priorities assigned<br>A vaccine will take six months post-pandemic to arrive; it will arrive in small batches |
| Example: Concern that staff on my team won't come to work:<br>My team includes…<br>Their concerns are…<br>The regional policy states…<br>Through the various phases of a pandemic, our threshold staffing needs will be… |

| IT IS TRUE THAT… |
|---|
| |
| |
| |
| |
| |
| |

| INFORMATION THAT IS MISSING … | Is this information available or will it remain unknown? |
|---|---|
| | |
| | |
| | |
| | |

## Phase 3 Worksheets Steps 3 & 4

What are the criteria we should use to judge the options?
(Answer in the following way…It is important that the decision…)

What is the relevant importance of these criteria?

| |
|---|
| Tips:<br>Focus on what is important at the decision-making (your) level<br>Focus on evaluative statements (it is important that… people should…)<br>Be as specific as possible<br>Include all of the important considerations on the list<br>Try to avoid duplication |
| Example: Vaccine distribution:<br>Support and minimize moral distress of those who will have to make these difficult decisions at the time of the pandemic<br>Declare conflict of interests among decision-makers<br>Follow national and provincial guidelines<br>Maintain the trust of each constituent group<br>Treat all people equitably (everyone gets in proportion to their need) |
| Example: Concern that staff on my team won't come to work:<br>Support team members in making hard decisions<br>Honour the various commitments that team members have to live up to as human beings<br>Maximize the availability of staff when the need is greatest<br>Discharge our professional duties |

| IT IS IMPORTANT THAT… | WHY IS THIS IMPORTANT TO YOU? | PRIORITY SETTING<br>1 = Crucial<br>2 = very, very important<br>3 = very important<br>4 = important |
|---|---|---|
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |
| | | |

## Phase 3 Worksheets Step 5

What are the possible ways of answering the question?

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

1.

2.

3.

4.

5.

6.

7.

8.

9.

10.

11.

## Phase 3 Worksheets Step 6

Evaluate each option against the most important criteria

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

| OPTIONS | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| Values | | | | |
| It is important that… | | | | |
| It is important that… | | | | |
| It is important that… | | | | |
| It is important that… | | | | |
| It is important that… | | | | |
| It is important that… | | | | |

## Phase 3 Worksheets Step 7

Articulate the decision and its justification.

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

| |
|---|
| The option we think is most justified is… |
| |
| The values this decision is based on are... |
| |
| These values are given priority because... |
| |
| Values that are traded off or sacrificed in this policy include... |
| |
| We think this balancing is justified because... |
| |

## Phase 3 Worksheets Step 8

Evaluate the decision against FH Pandemic Planning core values.

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

| Will this decision… | |
|---|---|
| Enhance trust between system and staff?<br>Enhance trust between FH and the public? | |
| Enable decisions to be made in partnership with those who are affected, particularly staff? | |
| Allow being open and honest about the process by which decisions are made and the values and assumptions that guide these? | |
| Ensure the messages sent from FH are clear and consistent, both internally and with other health regions and the province? | |
| Allow remaining within the project's scope, schedule and budget? | |
| Allow those closest to decisions to exercise discretion in the difficult decisions they make based on their understanding of the situation, providing them with decision tools and an understanding of the core values that should in principle guide their decisions and actions? | |
| Maximize the safety of those putting themselves at relatively greater risk of personal harm? | |
| Support making decisions on the best available evidence, ensuring assumptions made are well grounded and defensible? | |
| Ensure that the net harm to the public, through the spread of disease, disruption to necessary activity and function is minimized as much as possible? | |
| Meet the health care needs of the public, including saving the lives of those most at risk of dying – this includes maximizing the health system's ability to provide services when needed? | |
| Ensure that care decisions, including decisions about allocating scarce resources, are based on the same values/criteria for all care recipients across the region – so individuals in similar circumstances are treated similarly? | |

### ***Phase 4 Worksheets: Developing a Consultation Plan***

The agenda for the meeting might look like the following…

| Meeting agenda | | |
|---|---|---|
| Step | Description | Time |
| 1 | What other individuals or groups should be given the opportunity to participate in this decision process? | |
| 2 | For each, what should the nature of the participation be? Are they simply to be informed of our approach? Are they being consulted for their perspective? | |
| 3 | For each, what opportunity will they have to question the actual decision process and affect the decision agenda? | |
| 4 | For each, what education about the issue will be provided? | |
| 5 | For each, what information about our assumptions and guiding values will be provided? | |
| 6 | For those individuals/groups for whom this process may be foreign or uncomfortable, what process/forum will be provided to allow unhindered reflection on the issue? | |
| 7 | For each, what will we do with their feedback? | |
| 8 | For each, how will we report back on our decisions and on what we have done with their feedback? | |
| 9 | For each, what consultation mechanism/forum will be used? | |
| 10 | For each, who will be responsible for conducting the consultation? | |
| 11 | What resources will those responsible have for undertaking this consultation? | |
| 12 | What should be the timeline for the consultation? | |

A worksheet to help guide the conversation of this meeting is provided below.

What other individuals and groups should be asked to share their perspectives on the issue? What is the level of engagement required with the group? What is the best mechanism for receiving this input?

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

| Individuals or groups to be consulted | Specific purpose of consultation | How should consultation be conducted? | Priority of consultation |
|---|---|---|---|
| | | | |
| | | | |
| | | | |
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### *Phase 5 Worksheets: Undertaking the Consultations*

| | |
|---|---|
| Consultation Issue | |
| Decision team contact/lead | |
| Consultation lead | |
| Group being engaged | |
| Objectives of engagement | |
| Participant characteristics | |
| Participant recruitment and selection | |
| Agenda for meeting | |
| Discussion structure | |
| Frequency of meeting | |
| Method for participant input | |
| Authority of outcomes from minipublic | |
| Are any types of reasons to be excluded in the dialogue? | |
| Will past decisions be up for review? | |
| Will meeting format, structure, and agenda be open for discussion? | |
| Does the meeting structure build enough trust with the group to continue with processes of engagement? | |
| Is access to the discussion limited? If so, to whom and how is this justified? | |
| Will those whose concerns and perspectives will be discussed at the meeting be present? | |
| Will they be able to participate meaningfully – will they be able to be heard, have their perspectives genuinely engaged and responded to? | |
| If there is inequality in the participant group, what measures will be taken to overcome this? | |
| What efforts are being made to support existing vulnerable groups come together to share their perspective(s)? | |

### *Phase 6 Worksheets: Towards a Final Decision*

Sample Meeting agenda

The agenda for the meeting would follow the questions asked in worksheets 1-4. The agenda would be as follows:

| Meeting agenda | | |
|---|---|---|
| Step | Description | Time |
| 1 | Agree on the question being asked. | |
| 2 | What are the constraints/assumptions/facts that make up the context? | |
| 3 | What are the important considerations that should guide the answer? | |
| 4 | Of these, which are most important? | |
| 5 | Brainstorm options for answering the question. | |
| 6 | Analyze options against the values. | |
| 7 | Make a decision. | |
| 8 | Check decision against core values. | |
| **The objective of this process is to arrive at the best decision all things considered** (as opposed to any objectively right answer). In other words, should be able to say for any issue that the decision has been arrived at having taken time to carefully consider the facts of the case and what's important from all the key viewpoints – and this has been done with sincerity and integrity. | | |

## Phase 6 Worksheets Step 1

Confirm the question that is being asked…

| |
|---|
| Tips:<br>Ask yourself what question, if you had an answer to it, would provide clear, complete and meaningful direction for how to deal with the issue you are facing<br>Avoid questions that lead to yes or no answers, as these tend not to offer rich solutions to complex problems<br>Frame the question as how or what should |
| Example 1:<br>Issue – Vaccine distribution<br>Question: Within the priority groups established by the federal government, how should FH allocate the vaccine? |
| Example 2:<br>Issue- concern that staff on my team won't come to work<br>Question: what approach should I take to our team's staffing policy at the height of the pandemic? |

## Phase 6 Worksheets Step 2

What are the salient facts / assumptions / constraints that make up the context of this question?

| |
|---|
| Tips:<br>Focus on those givens that all would agree on<br>Try to leave out evaluative statements (it is important that… people should…) – as these will be covered in the next step<br>Focus on those statements that include variations on the verb "to be" – i.e. "was", "is" or "will be" statements |
| Example: Vaccine distribution:<br>Federal and provincial plans provide a prioritized list of the groups within society that should receive the vaccine<br>The provincial and federal lists are consistent in terms of groups identified and priorities assigned<br>A vaccine will take six months post-pandemic to arrive; it will arrive in small batches |
| Example: Concern that staff on my team won't come to work:<br>My team includes…<br>Their concerns are…<br>The regional policy states…<br>Through the various phases of a pandemic, our threshold staffing needs will be… |

| IT IS TRUE THAT… |
|---|
| |
| |
| |
| |
| |
| |

| INFORMATION THAT IS MISSING … | Is this information available or will it remain unknown? |
|---|---|
| | |
| | |
| | |
| | |
| | |
| | |

## Phase 6 Worksheets Steps 3 & 4

What are the criteria we should use to judge the options?
(Answer in the following way…It is important that the decision…)

What is the relevant importance of these criteria?

Tips:
Focus on what is important at the decision-making (your) level
Focus on evaluative statements (it is important that… people should…)
Be as specific as possible
Include all of the important considerations on the list
Try to avoid duplication

Example: Vaccine distribution:
Support and minimize moral distress of those who will have to make these difficult decisions at the time of the pandemic
Declare conflict of interests among decision-makers
Follow national and provincial guidelines
Maintain the trust of each constituent group
Treat all people equitably (everyone gets in proportion to their need)

Example: Concern that staff on my team won't come to work:
Support team members in making hard decisions
Honour the various commitments that team members have to live up to as human beings
Maximize the availability of staff when the need is greatest
Discharge our professional duties

| IT IS IMPORTANT THAT… | WHY IS THIS IMPORTANT TO YOU? | PRIORITY SETTING<br>1 = Crucial<br>2 = very, very important<br>3 = very important<br>4 = important |
|---|---|---|
| | | |
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| | | |
| | | |

## Phase 6 Worksheets Step 5

What are the possible ways of answering the question?

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

1.
2.
3.
4.
5.
6.
7.
8.
9.
10.
11.

## Phase 6 Worksheets Step 6

Evaluate each option against the most important criteria

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

| Options | 1 | 2 | 3 | 4 |
|---|---|---|---|---|
| Values | | | | |
| It is important that… | | | | |
| It is important that… | | | | |
| It is important that… | | | | |
| It is important that… | | | | |
| It is important that… | | | | |
| It is important that… | | | | |

## Phase 6 Worksheets Step 7

Articulate the decision and its justification.

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

| |
|---|
| The option we think is most justified is… |
| |
| The values this decision is based on are... |
| |
| These values are given priority because... |
| |
| Values that are traded off or sacrificed in this policy include... |
| |
| We think this balancing is justified because... |
| |

## Phase 6 Worksheets Step 8

Evaluate the decision against FH Pandemic Planning core values.

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

| Will this decision… | |
|---|---|
| Enhance trust between system and staff?<br>Enhance trust between FH and the public? | |
| Enable decisions to be made in partnership with those who are affected, particularly staff? | |
| Allow being open and honest about the process by which decisions are made and the values and assumptions that guide these? | |
| Ensure the messages sent from FH are clear and consistent, both internally and with other health regions and the province? | |
| Allow remaining within the project's scope, schedule and budget? | |
| Allow those closest to decisions to exercise discretion in the difficult decisions they make based on their understanding of the situation, providing them with decision tools and an understanding of the core values that should in principle guide their decisions and actions? | |
| Maximize the safety of those putting themselves at relatively greater risk of personal harm? | |
| Support making decisions on the best available evidence, ensuring assumptions made are well grounded and defensible? | |
| Ensure that the net harm to the public, through the spread of disease, disruption to necessary activity and function is minimized as much as possible? | |
| Meet the health care needs of the public, including saving the lives of those most at risk of dying – this includes maximizing the health system's ability to provide services when needed? | |
| Ensure that care decisions, including decisions about allocating scarce resources, are based on the same values/criteria for all care recipients across the region – so individuals in similar circumstances are treated similarly? | |

### *Phase 7 Worksheets: Decision Follow Up*

The agenda for the meeting might look like the following…

| Meeting agenda | | |
|---|---|---|
| Step | Description | Time |
| 1 | Who will be affected b this decision? | |
| 2 | Who will be required to carry out this decision? | |
| 3 | What education do they need? | |
| 4 | Who might be morally compromised by the decision? | |
| 5 | What supports might help them deal with this challenge? | |
| 6 | How can we ensure these supports are put in place? | |
| 7 | What recourse will those who disagree with the decision have to appeal the decision or to have their perspective meaningfully engaged? | |

### Phase Seven B Worksheets

The following worksheets (similar to those in the pre-work section) are provided to help guide each

## Develop an implementation, communication and downstream support plan

| |
|---|
| Tips: |
| Example: Vaccine distribution: |
| Example: Concern that staff on my team won't come to work: |

| Implementation | | |
|---|---|---|
| Step | Description | Lead |
| | | |
| | | |
| | | |
| | | |

| Communication | | | |
|---|---|---|---|
| Individuals or groups to be informed | Key messages | Communication vehicle | Lead |
| | | | |
| | | | |
| | | | |
| | | | |

| Downstream Support | | | |
|---|---|---|---|
| **Who will be affected by the decision?** (Who will have to carry out the decision or change their practice patterns as a result) | Is the decision likely to cause difficulty to those affected? | What would assist those affected? | What support can be provided in this direction? |
| | | | |
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| | | | |

## The Emergence of Core Values and Moving Towards Reflective Equilibrium

The conventional approach to thinking about the ethics of pandemic planning has been to articulate the content and process values that should guide decision-making. This approach differs from this convention in that it allows the values of an organization to emerge on their own. That is, as a number of issues are raised in this systematic way, it is anticipated that themes of important considerations for the group will emerge. These can be thought of as core values for the group or organization and should be articulated as such. They can then be used as reference points against which to check each future decision made.

This reflection on values then moves both forward and backward. It moves forward in that as new issues arise, they can be evaluated from the perspective of the core values that have emerged. It moves backwards in that as values are applied, what they mean in practice becomes clearer, and the list of core values itself develops. This development can happen in that the importance of the values in the list might be reinforced, a clear prioritization within the values list might happen, or it might be discovered that there are other important values that are not reflected on the list.

For example, on reflecting on the question of what types of beds to use in an alternate care site during a pandemic at Fraser Health, important values include ease of cleaning, degree of lifting required by staff, portability, risk of falling, patient comfort and the acceptability of different types of beds to the public. Ease of cleaning relates to infection control and is a specification of the value of public safety and well-being. Risk of falling also relates to the value of public safety and well-being. Degree of lifting required by staff can be seen as specifications of the values of safety and well-being of staff at risk and trust between the staff and the system. But patient comfort and the acceptability of different types of beds to the public does not relate easily to any of the FH values articulated. Should there be another value on the list that takes this consideration into account as very important? Is this criterion really not that important in the context of a pandemic and should it not be used to evaluate bed options? Or is there an existing value whose meaning should be stretched to include this consideration? As this question is encountered, decision-makers will have moved closer to a position of reflective equilibrium.

The conventional approach to ethics can still be very useful in that, where core values have not yet emerged for an organization, the values articulated in the literature can be used as the values check. It will also be important to ensure that the values developed by an organization to govern pandemic planning stand up to the values articulated in the literature.

The core values that emerged in the process of Fraser Health's pandemic planning work and the values identified by the Joint Centre for Bioethics at the University of Toronto are provided as examples below.

| Core Values of Fraser Health Influenza Pandemic Planning (Listed in alphabetical order NOT order of priority) | |
|---|---|
| Value | Description |
| Clear and consistent communication | Ensuring the messages sent from FH are clear and consistent, both internally and with the province and other BC health regions |
| Collaboration | Making decisions in partnership with those who are affected, particularly staff |
| Evidence | Making decisions on the best available evidence, ensuring assumptions made are well grounded and defensible |
| Fairness in the distribution of resources | Ensuring that care decisions, including decisions about allocating scarce resources, are based on the same values/criteria for all care recipients across the region – so individuals in similar circumstances are treated similarly |
| Preventing untimely death and treating those that are ill | Meeting the health care needs of the public, including saving the lives of those most at risk of dying – this includes maximizing the health system's ability to provide services when needed |
| Project stewardship | Remaining within the project's scope, schedule and budget during the planning phase and ensuring sustainability of the project action items after planning is complete |
| Public safety and well-being | Ensuring that the net harm to the public, through the spread of disease, disruption to necessary activity and function is minimized as much as possible |
| Respect and support for decision-makers | Allowing those closest to decisions to exercise discretion in the difficult decisions they make based on their understanding of the situation, but providing them with decision tools and an understanding of the core values that should in principle guide their decisions and actions |
| Safety and well-being of staff at risk | Maximizing the safety of those putting themselves at relatively greater risk of personal harm |
| Transparency | Being open and honest about the process by which decisions are made and the values and assumptions that guide these |
| Trust | Enhancing trust between system and staff<br>Enhancing trust between FH and the public |

## Developing a Public Engagement Philosophy and Strategy

In this section we will explore different models of public engagement, the strengths and drawbacks of these, and practical lessons that regional leaders would be wise to keep in mind in moving towards a public engagement philosophy and strategy. This will not be an easy task. Abelson et al., identify a number of challenges with engaging public deliberation within the health setting. One of the most daunting is the absence of a strong infrastructure for public engagement within public health institutions.[67] Moreover, in their research, Abelson et al. have found that very little work has been done to date on the rigorous and systematic evaluation of public engagement methods in the health context.[68]

A complicating factor is that public engagement is important for multiple goals that include meeting the needs of democratic legitimacy as well as getting a better understanding of the health needs of the community to aid in the provision of efficient and effective health care services.

There exist a large variety of models of citizen engagement and these models vary with respect to several features. Choosing between models involves making decisions about these features, but these decisions are philosophical, not practical. Therefore, before addressing the question of what models or types of public engagement to choose, a public engagement approach will have to consider these features and take a philosophical position on the following questions...

- What work is the public engagement forum (minipublic) is meant to do?
- Who should participate in the forums, the number of participants involved and how should these individuals be recruited?
- To what degree will the forum be deliberative?
- At what stage of the decision-making process will the group convene and what issues will the participants discuss?
- How will the discussion be structured, and what will be the frequency and type of interaction?
- What decision-making authority the group will have?
- What will the educative component include?

### *What work is the public engagement forum (minipublic) is meant to do?*

Health regions will have to come to terms with the purpose of the public engagement initiative.[69] Is it to improve the legitimacy and accountability of decisions and decision

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[67] Abelson et al. 2003 p. 248.

[68] Abelson et. al. 2003.

[69] Abelson et al. offer a four dimensional framework for evaluating any deliberative process: representation, structure of process, information used, and decisions and outcomes. (They develop their

processes? Is it to better understand public needs and expectations? Is it to improve effectiveness of existing programs? Is it to enhance the epistemic quality of decisions? Is it to provide education or to communicate decisions taken? Is placate those clamouring for greater public involvement?

I have suggested that central to the philosophical question of the purpose of forums are the issues of governance and democratic legitimacy on the one hand, and efficiency and effectiveness on the other. It is the importance of these values that should actually guide how public engagement ought to be understood and around which public engagement strategies ought to be formulated. In terms of governance and legitimacy, Burgess writes…

> *Governance necessarily embodies explicit or implicit judgments about the relative weight of the interest and concerns expressed by various groups, including the public. That said, there is a tendency in most industrialized countries to depend on "experts" to describe and assess the benefits, risks and merits of research and*

---

framework from work done by Renn and Webler (who building on the theoretical normative work of Hannah Arendt and Jürgen Habermas), and the work of Beierle).

> *development, particularly in areas of high technology... The presumption often appears to be that government itself adequately represents public interests. If and when the public is consulted, it is (generally) to identify where they will use a technology-rather than whether to use the technology-to identify concerns with its use, or to reduce the influence of "interest groups." This attitude and risk perception research sees public interest as a phenomenon to be described, evaluated and moved, but not engaged.*[70]

I believe this assessment in the area of health technology can be extended to system-level decision-making where there may be the implicit understanding that public interests are already served by regional leadership. And with Burgess, I would argue that this presumption is mistaken. So one purpose of a region's efforts at public engagement should be to improve the democratic legitimacy of decisions made at this level.

As for questions of efficiency and effectiveness, I begin with the assumption that the raison d'etre of the system – advancing health and well-being – is not objective but evaluative. Thus, to advance the health of members of the community, the region must have some understanding of what members believe the ends of human life to be, which in turn requires their political participation. If the objective of the system depends on an interpretation of health and wellbeing, we need to understand what health and wellbeing look like for members of the community and how they see this being achieved if we are to meet this need efficiently and effectively. Leaders will need to engage the community help understand its own sense of health and what meeting health needs will look like.

Second, in a context where people have a spectrum of values, beliefs and understandings of what a meaningful life involves, possess a wide range of capacities to attain well-being, and occupy different places in a fairly broad hierarchy of socio-economic status, there will be tremendous variance in the health needs of different people. In diverse contexts, the problems of ethnocentrism, androcentrism, ageism, ableism, "medicalism" and other forms of discrimination based upon a misunderstanding of the moral authority of some viewpoints can be exacerbated. Equity involves recognizing differences in the needs of people and meeting the respective needs of different individuals and groups in a situation sensitive manner. To live up to this value, leaders will have to find ways of hearing the voices of the vulnerable in the development of their responses to meeting needs.

Third, meaningful public engagement and participation in the decision process is itself a means of empowering people over their own destiny. It is a way of demonstrating meaningful political self-government, which can by itself have salutary health effects. Leaders can use this vehicle as a means of actually generating health gains.

And fourth, healthcare is where identity is forged. Their identity is important to Canadians and they see the healthcare system as a representation of this. But identity is

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[70] Burgess 2003, p. 2.

not static. If growth and self-understanding comes from resolving values in tension, then leaders have an obligation to provide support on this journey.

### *Who should participate in the forums, how many participants should be involved, and how should these individuals be recruited?*

Representation refers to questions about the sample of participants involved in the initiative: what understanding of representation underlies the selection, is geographic and demographic representation accounted for, have participants been actively chosen or self-selected, and so forth. One challenge involves dealing with strong interest groups who seek to use the forum to sway the discussion and outcome.[71] Another challenge is achieving appropriate representation, especially in the context of low interest in participation.[72]

The answer to the question of purpose will determine who should participate in engagement initiatives. Writing in the context of genetic technologies, Burgess writes citing Sherwin, that it is important to "distinguish product consumers (i.e., stakeholders who need safe, reliable, affordable products, accurate information and protection from exploitation) from citizens concerned with the broader social, cultural, or environmental effect of developing or distributing those products."[73]

### *To what degree will the forum be deliberative? Types of deliberative forums*

> *"The essence of democracy itself is now widely taken to be deliberation, as opposed to voting, interest aggregation, constitutional rights, or even self-government. The deliberative turn represents a renewed concern with the authenticity of democracy: the degree to which democratic control is substantive rather than symbolic, and engaged by competent citizens."*[74]

Non-deliberative models tend towards mechanisms of mass participation and include such practices as advertisements, leaflets with return slips, telephone hotlines, opinion polls and surveys of various forms.[75] The advantages of these mass approaches include the potential for a wider scope of representation and the possibility of making generalizations through statistical analysis about the population from which the information is gathered.

The challenge with these kinds of approaches, as has been alluded to earlier, is the collective difficulties of aggregative models and the absence of deliberation and thereby, a decrease in democratic legitimacy. According to Mullen, these relatively simple

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[71] Abelson et al. (2003) p. 248.
[72] Abelson et al. (2003) p. 248.
[73] Burgess (2003).
[74] Dryzek (2000) p. 1.
[75] Mullen (1999).

techniques have been predominantly used as public participation mechanisms within the health context.[76]

Deliberative models include citizens' juries and planning cells. I offer a brief review of several deliberative models, but many more can be found at such resources as the (American) National Coalition for Dialogue and Deliberation.[77] All of the deliberative models have in common a focus on the uptake of information, the sharing of views, the listening to the views of others, and the engagement of different perspectives before coming up with a decision.

### ***Citizens Juries and Planning Cells***

Here groups of 12 to 24 participants are randomly selected to represent the community. These individuals meet over several days during which they are informed about the issue in question, they hear evidence from witnesses to whom they can direct questions, and then the group deliberates and comes up with a solution that s presented to the sponsor. Often these groups meet routinely (several times per year). These models allow for broader perspectives to be brought to bear on policy decisions and, as representative of the community, improve the democratic legitimacy of decisions. Challenges include that of representation and the groups' lack of formal power.

### ***Deliberative Polling***

Developed by James Fishkin, this model takes the idea of an opinion poll and enhances it with a deliberative exercise. The model involves taking a large number of people selected randomly and polling their views on an issue. The group then comes together over a period of two to three days to engage in structured deliberative dialogue. The group is then polled again at the end of the exercise. This approach perhaps better meets the challenges of representation. The model is resource intensive and logistically challenging.

### ***At what stage of the decision-making process will the group convene and what issues will the participants discuss?***

As the decision framework above suggests, there are a number of stages in the deliberation process, beginning with the identification of the issue in question and the decision agenda, gathering and evaluating evidence available about the issue, engaging in a process of reason-exchange and deliberation, making a decision, and then communicating and supporting the decision made.

When it comes to the question of setting the decision-making agenda, Burgess suggests that…

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[76] Mullen (1999).

[77] See www.thataway.org/resources.

> *defining issues inevitably rules particular interests "in" or "out." Consequently, issue definition is where expert-based approaches to policy development typically begin to bias deliberations and/or consultations. This means that the initial, and possibly most important, challenge to non-expert-based policy discussions in technical areas is the creation of a framework that recognizes citizen interests and ensures representative participation. Simply identifying an issue (e.g., labeling GMOs) by fiat and relevant stakeholders (e.g., environmental groups) according to the issue is inadequate; the range of interests, which includes both hopes (e.g., a reduction in pesticide use) and concerns (e.g., unintended environmental harm), will be incomplete. Participants will be engaged from, and limited to, the perspective of particular roles (e.g., consumers) rather than as citizens with interests based on citizenship and rooted in the particularities of their lives.*[78]

Accordingly, he suggests that a broader approach to agenda setting is required. The particular approach to this he recommends for this is focus groups.

> *The focus group model of consultation presents a useful tool for identifying a diversity of interests within a particular field. In focus groups, participants have an opportunity to shape discussion, as well as reflect on and respond to comments by other group members. The shared understandings of aspects of life experiences that result from these conversations enhance participants' abilities to learn from each other. Consequently, focus groups provide an opportunity to expand the breadth and depth of issues covered, for study participants, as well as researchers.*

### *How will the discussion be structured, and what will be the frequency and type of interaction?*

Evaluation of the structure of the procedures includes such questions as, what will interactions look like, how often will they occur, what access to setting the agenda will participants have, what will be the nature of the deliberation in the discussion, how much time will be allotted for this, what is the credibility/legitimacy of the process?

### *What decision-making authority the group will have?*

Another important question that the approach will have to consider is what will be done with the decisions that the engagement forum arrives at (assuming that the minipublic is tasked with providing solutions to problems)? Will they have exclusive authority over the decision? Will the outcome simply be taken under the advisement of decision leaders?

One difficulty here is ensuring accountability when the process is but one element of a complicated decision process that takes place over a large period of time.[79]

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[78] Burgess (2003).

[79] Abelson et al. (2003) p. 248.

A more serious concern is that of window dressing. That is, building a public engagement infrastructure as I have argued that regions must do, but without directly injecting actual decision-making with the outcomes of deliberative forums will give the appearance of meaningful engagement, but will not meaningfully honour those engaged, and by extension those broader groups whom the participants are intended to represent.

### *What will the educative component include?*

Information is evaluated in terms of the characteristics of the information itself and the information giving process, the accessibility, readability, digestibility and selection and presentation of the information, who chooses the information, how the experts are chosen, how the information is to be interpreted, and the amount and adequacy of the time provided to take up and discuss the information given.

A challenge here is overcoming the bias involved with selection of experts and information.[80]

### *Frameworks for choosing criteria*

Mullen offers a framework for choosing between participation methods in the form of a series of questions provided under three headings.[81] Under *appropriateness* she suggests asking how appropriate the method is to the questions or issued being discussed, how the method takes into account what meaning the question or issue likely has for participants, what form of response the participants are permitted to provide, whether the method seeks constrained or unconstrained choices, whether the intensity of participant preferences is accommodated, and how the results will be interpreted. Under *aggregation* she suggests examining questions of inter-respondent inequity. Finally, under *ease of use*, she suggests asking how easy the technique is for participants to use, how transparent the technique is to both respondents and investigators, and what expertise is required to implement the model.

## Organizational Policy on Policy

Policies are communication vehicles for the values which leadership wishes to foster throughout the organization. Organizational policies represent an opportunity to articulate and clarify values and resulting processes, which apply across the organization.

The process for developing organizational policies should reflect organizational philosophy. In an organization that is committed to teamwork and inter-disciplinary, cross-functional performance, the policy development process should mirror this commitment.

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[80] Abelson et al. (2003) p. 248.
[81] Mullen (1999).

## POLICY

Policies shall form the written basis of the organization's operations, secondary to legislation, and the organization's bylaws. They shall serve as guiding principles for decision-making. Policies describe what must and must not be done but in general do not describe how the work is done. They set limits, assign responsibilities and set out expectations.

Policies shall exist at a Board or an Organizational level, reflecting the overall organization and affecting everyone in the organization. Policies shall be formal and authoritative.

The Executive Management Team shall provide the framework for Policy and Standard development, implementation, maintenance and archival. Organizational policies and standards should be developed by the manager most responsible for organizational compliance. Final approval should be given by the executive management team member responsible for the area developing/recommending the policy. This person should receive notice of revision times following policy implementation. Organizational policies and standards shall be reviewed every three years, or more frequently if needed, to ensure their continued appropriateness and applicability.

Management of organizational policies and standards shall be delegated to one person. Policies shall be stored and maintained on one database by this person. This person shall also notify people when Policies under their responsibility are due for renewal/revision.

## POLICY WRITING:

A *policy* is a primary communication device, therefore, it shall be oriented to the main users (i.e. *readability and the amount of detail*).

Brief statements with emphasis on clarity shall be utilized.

The policy should be stated "who" is to do "what" using the imperative form of verbs in the Policy portion *(i.e. The Director must sign..., Visitors shall report to...).*

The policy should not be stated with possibilities of what someone might do.

For the procedure portion of the policy, individuals who will carry out the task or tasks required to implement the policy should be identified using the directive form of the verb *(i.e. The Manager obtains... The Vice-President writes...).*

## PROCEDURE

It is expected that those engaging in policy writing will engage in discussion that answers the following questions...

Date of Discussion:______________________

Participants:

__________________________________________________________

__________________________________________________________

| Question: | Team Response |
|---|---|
| What is the specific problem for which A policy solution is being sought? | |
| What are the relevant facts, as we believe them to be? | |
| What considerations (values) are considered most important, that the policy solution should take into account? | |
| What are the different policy options for answering the question? | |
| Which option is most consistent with (and therefore justified according to) the most important considerations (values)? | |

***FORMAT***

Policy decisions should take on the following format…

| | |
|---|---|
| (Page # of total pages) | |
| Policy Title | |
| Approved By | |
| Date of Approval/Revision | |
| Policy Decision | |
| Definitions | |
| The key values this policy is based on are… | |
| The values have been prioritized in this way… | 1.<br>2.<br>3. |

| | |
|---|---|
| | 4.<br>5. |
| Accordingly, the policy seeks to balance these competing interests… | |
| These values are least supported by the policy option… | |
| This balancing is justified because… | |
| References | |
| Procedures and Forms attached<br>(To include education, communication, downstream support, evaluation, and sustainability plans for the policy) | |

## A Decision Evaluation Form

The following form can be used to get a sense of the justification for a system-level decision:

| Values | Test Questions | Response |
|---|---|---|
| Effectiveness,<br>Equity,<br>Solidarity,<br>Canadian Identity | Does the decision make explicit what decision is made? | |
| | Does the decision make explicit what values the decision is based on? | |
| | Does the decision make explicit what values are sacrificed? | |
| | Does the decision make explicit how this balance is justified? | |
| | Is the deliberative space wherein the decision was made discursive in that no reasons are excluded from engagement and where deliberative uptake of diverse perspectives is ensured? | |
| | Is the deliberation recursive in that both past decisions and the very framework for decision-making are open for review? | |
| | Is the deliberation inclusive such that those affected by the decision could agree to continue to participate in the ongoing policy-making process? | |
| | Do citizens have access to the process? | |
| | If access is available, to what extent do citizens have the skills to engage in the discussion such that they are able to have their perspectives genuinely understood and responded to? | |
| | If there exists inequality, to what extent has the policy-making institution created forums for public consultation that overcome the existing inequalities? | |
| | What efforts have been made to *support* existing sub-publics working to empower them with that which is required to overcome existing inequalities? | |
| | Have the process values for the working of the leadership team charged with the responsibility for making the decision in question been made explicit? | |
| | Have these values have been meaningfully honoured by participants in the decision process? | |

## Glossary

### Accountability

Answerability of an individual or group to an authority for the kind and quality of decisions made or actions taken.

### Care for the Vulnerable

The idea that those in need have a greater claim on resources (time, attention, capital, human resource hours, care and concern) than those relatively more well-off.

### Consensus

Coming to shared agreement on an issue among a group. Different from shared understanding (where everyone achieves the same perception of the issues, but may disagree on solutions) and agreement to proceed (where everyone in a group agrees to move forward in a certain direction, but may not agree that the solution chosen is in fact the best or most appropriate).

### Common Good

The understanding that humanity is somehow connected and the well being of a community is distinct, separate from, and more than the well being of each individual constituent.

### Creating Moral Space and Time

Ensuring that an appropriate forum is available for an appropriate period to discuss important ethics issues.

### Duty to Accommodate (also Proportionality)

Responsibility of society (or agents of society, such as health authority) to respond to the needs and personal circumstances of healthcare providers in times of crisis – commensurate with the degree and conditions of the crisis.

**Duty to Care**

Responsibility of healthcare providers to provide care to members of the community, even when this involves exposure to some risk on behalf of the health care provider.

**Efficiency**

Achieving a desired objective using the fewest possible resources – thereby with the least waste of resource. Efficiency is never an end in itself, and always a means to achieve some greater value.

**Egalitarianism – Democratic (or Liberal)**

This approach guarantees equal basic political liberties to all, strives to achieve equal opportunity and places constraints on inequality. On this view, from noted philosopher John Rawls, all human beings are morally equal in that they ought to have equal access to the opportunities that allow us to flourish. Because we can't be said to deserve the health, economic, social or political status we are born in to, society ought to redistribute goods in order to ensure as much as possible that the differences that result in society are deserved, not conferred. So goods in society ought to be distributed equally in society unless an unequal distribution would result in making the worst off better off than they would have been under more strictly equal distributions.

**Egalitarianism – Radical**

Similar to the liberal egalitarian account, this approach suggests that as human beings we are all morally equal and as such equally deserving of the opportunity to flourish as human beings. Again, because we cannot be said to deserve in any meaningful way the starting points we are born into and because we ought to have an equal opportunity to flourish, society must redistribute goods in a way that makes up for any arbitrary discrepancies in allocating goods that occur in the natural lottery. A significant difference between this approach and that of the liberal egalitarian is that while in the latter the goal is to maximize the well being of the worst of in society, even at the expense of inequality, this approach requires that allocation strategies aim at equalizing outcomes, even if this means that those who are worst off would be less well off in the more equal state than they would have been in an unequal distribution pattern. Resources should be distributed to those whose health status is most compromised to bring them up as close as possible to the health status of the rest of the members of society.

**Empathetic Understanding**

Understanding the world from' another's point of view. A necessary correlate of having unconditional positive regard for others as making an effort to understand and appreciate another's views involves (and some might argue is what leads to) accepting that she is an individual who, like all of us, has developed her views based on particular circumstances that she has experienced.

**Equal Access**

Usually refers to the idea that everyone should be able to have the same access to health care resources as commensurate with their need of those resources (as opposed to other criteria such as proximity to the resource, ability to pay, political authority, social status, etc.)

**Equal Opportunity**

Liberal egalitarian notion that refers to the egalitarian ideal that the goal of resource distribution should be enabling all members of society to have equal chance at resources needed for living a good life, broadly understood.

**Equal Outcome**

Radical egalitarian idea that goal of resource distribution should be getting everyone to the same status of health and well being.

**Ethics**

The critical examination of our values. In particular, we can break ethics down into three different types of questions: descriptive, prescriptive and applied.

**Ethics – Applied (or Practical)**

Is about bringing our values and beliefs to life. This area of ethics asks us take note of the gap between the values that we are living by and the values we feel we should be living by, and to explore how it is that we can bring the decisions and actions in our lives more in line with the latter.

**Ethics – Descriptive**

Exploring the values and beliefs that actually do guide our decisions and actions.

**Ethics – Prescriptive**

Asks what are the values that we cherish and the beliefs we really hold to be true? It is about asking the question, what are the values we hold dear, that we want to live by that we would like the whole community to live by? It is prescriptive in that it is like we are writing a prescription for how the world ought to live.

**Excellence**

Striving for excellence by constantly improving the quality of care we can provide to our residents, better meeting our residents' needs and to the growth and capacity building of our staff. This requires ongoing learning, research and training of all staff at all sites.

**Fairness**

Those who are in similar circumstances should be treated similarly, unless there is good reason to treat them differently. Only morally relevant differences justify different treatment. In some moral traditions, fairness also includes a special duty to those who are most vulnerable in society – those without resources necessary for living healthy, peaceful lives.

**Following Institutional Policy**

There are many moral guides in the healthcare setting, including the various professional codes of ethics, various legislation, organizational values and organizational policies. These guides offer direction for what various institutions and organizations feel are the appropriate values that should guide conduct. While these guides are a very important resource when doing an ethics analysis, they do not always offer consistent direction and are not always sensitive to the contextual features of actual situations. Accordingly, it is important to understand and make decisions in line with such guides as institutional policy. However, it is important to remember that the main justification for following a policy (or a law) is that it the policy itself is based on justified values. If following a policy leads to action that thwarts key values, then following it would not be justified.

### Health and Well-Being

Attending to the physical, emotional, social and spiritual needs of those who are cared for and who provide care within the organization in accordance with best practice standards. It is recognized that while one's physical health is an important factor in one's overall well-being, it is far from the only dimension of human health. Because our goal is to advance the well-being of those in our community (care recipients and givers), and because what this means will depend upon the individual's understanding of what a meaningful life looks like and be informed by other dimensions of well-being (spiritual, psychological, social, etc.) we take a broad view of healing that requires us to consider these other dimensions in developing care plans. We deliver these services with professionalism – competently and compassionately.

### Inclusiveness in Discussion

Seeking to include as many legitimate perspectives as there are, from the extremes to those in between, in working through a problem.

### Integrity – Organizational

Ensuring that all the decisions made and actions taken at the boardroom and the bedside are made paying explicit attention to and in keeping with the values of residential care at PHC – recognizing that value trade-offs will be required from time to time. This value is about being clear on our talk and then walking that talk on a regular basis.

### Intellectual Honesty

Being truthful about the extent and limits of knowledge or expertise.

### Libertarianism (or Right to Liberty)

The fundamental premise of libertarianism is that as individuals, we all own ourselves. Our bodies are our possessions and we ought to have the exclusive right to do with our bodies as we please. The only limitation of this right is that we must limit our actions such that we do not violate anyone else's ownership rights to their bodies. This premise is then extended to the things we justly come to claim as our property or that we have a hand in making. Thus, if I lay claim to some land – say by trading for it or by discovering it in its previously unowned state – build a house and so on, these possessions that I have come to own are extensions of myself. I have exclusive ownership of them and no one ought to be able to infringe upon these property rights of mine. Similarly, I have no justification to interfere with anyone else'. Favours a distribution of goods on the free market. That is, there is no room for society to interfere with private interests to develop sell or purchase the vaccine, irrespective of equality or social consequences. Thus, if you can afford it, you should be free to trade for it in the market place.

### Non-Abandonment and Nurturing Relationships

In the end-of-life context, two crucial values of special importance to families are the nurturing of relationships and the commitment to provide care for the patient and their supports at this difficult time. Based on these values it is important that whatever decisions are made and steps are taken, they be as sensitive to family dynamics as possible and they involve assurance to the family that even though aggressive treatments may not pursued, care for and attention to the patient will always be provided.

### Patient Benefit

Patient benefit is about advancing the well-being of the patient. The challenge with this value, implicit in the comments above, is that what well-being involves is a subjective assessment – so the question arises, well-being from whose perspective? As well, in the culture of western medicine, well-being has traditionally focused on the physiological functioning of the body – the question is, how are the emotional, spiritual, relational needs of the patient informing discussion of patient benefit?

### Professional Competence

Having and using the technical expertise, including knowledge and skill base, to carry out professional roles at accepted standards of practice, based in the context of the values of the patient, the institution and the organization. In the context of the team approach to health care delivery, part of competent care is ensuring the team has a shared understanding of the goals of care for a patient and room is provided for team members to identify ethical issues with aspects of the care plan, and if necessary, to ask to be removed from a care plan they feel morally problematic (assuming other healthcare providers can be found to provide the necessary care).

### Reciprocity in Crisis

Ensuring that the basic needs of individuals are met commensurate with the degree that their freedoms may be taken away during times of crisis.

### Relationships and Community

Recognizing the interconnectedness of all those who serve and are served by healthcare institutions, and nurturing the relationships through which care is planned, delivered, and received – relationships without which care planners and providers would not have work and/or would be deprived of the opportunity to serve their calling, and care recipients would not receive the care they need to flourish in times of challenges to their well-being. This value recognizes that we need relationships to live our lives and grow as human beings and is about taking proactive organization-level action to strengthen the relationships of all the people in the health care community.

### Respect for the Dignity of Others

Respecting the worth of all human beings, with special attention to vulnerable members of the community. This value recognizes that no matter one's perspective, religious or cultural background, or socio-economic status, one's life is valuable and deserves to be treated with compassion and care.

### Respect for Liberty

Recognizing an individual's basic rights to freedom of speech, movement, association, etc.

### Respect for Patient Autonomy

Respecting the deeply and genuinely held values and beliefs of the patient and having decisions about the care of the patient be guided by these values and beliefs even if the resulting decision is inconsistent with what care providers may have chosen. When a patient is not competent, requires engaging in a process to determine from whatever reliable sources are available what the values and beliefs of the patient were and what their wishes might have been if they were competent to make the decision in question directly. The process requires of those involved (loved ones, family and staff) the difficult task of recognizing and setting aside their own values and beliefs and trying to see the world as much as possible through the patient's eyes.

**Respect for Privacy (also Confidentiality)**

Not interfering in the personal space of individuals or groups without their consent or just cause.

**Respect for Professional Integrity**

Health care professionals are moral agents who have their own values and beliefs about what meaningful life looks like how to best to pursue it. These values and beliefs can include personal convictions as well professional ones, such as found in professional codes of ethics and standards of practice. Wherever possible care providers should not be forced to participate in care plans they find excessively morally compromising, at least when it is possible to involve other care providers who are more comfortable with the care plan.

**Safety**

Absence of risk to well being. Commonly narrowly construed as risk to physical well being, but extends to holistic well being, including psychological, emotional, and spiritual dimensions.

**Social Utility**

According to this view, the lives of all presently existing and future human beings are equally morally valuable in that everyone's happiness is equally morally important. What we need to look for in determining fair distribution strategies is that allocation pattern that results in the best outcome for all. How do we allocate resources? Well we look at all of the distribution patterns available to us, add up the good that results from each – where the consequences for each person are weighed and where every individual can get a maximum of one unit of good, subtract the harm that results from each, and then select that option that results in the most net good. So the goal is to look for that strategy whose consequences allow for the greatest overall good for the greatest number.

Worries with this approach include the fact that it is often difficult to know in advance what the consequences of a given pattern of distribution will be, that it is difficult to weigh the relative good and relative harm that results from saving the life of one person while allowing another to die, that good and harm are themselves value-laden notions such that it is difficult to make objective calculations as this approach requires, and finally that this approach is counter-intuitive in some respects – for example, if two patterns of distribution result in equal outcomes then there is no moral difference between the two on this approach, even if the most vulnerable in one arrangement are treated poorly, while in another their lot is significantly improved.

### Solidarity

The union of interests, goals and means of a group. Working together to achieve shared interests.

### Spirituality

Nurturing the human spirit of all people, care givers, care recipients, and families alike. This value is about attending to that subtle/intangible dimension of the human being, often called the soul, wherein is found peace and which is the seat of our creativity, compassion, love, inspiration and solace. It is where we experience our connection to other members of the community. Most would agree that having a meaningful life requires paying attention to one's spirituality, however this is understood. Although the value can be understood as one dimension of the holistic well-being of the person, because of the organization's explicit faith-based perspective, it is identified as guiding value in its own right.

### Stewardship

The careful management and distribution of community resources. This value is about taking good care of the resources, both human and material, that have been invested with the organization. It is not only about resource allocation, but also about careful and deliberate modeling and direction setting for how resources should be established and used to serve and advance the interests of the broader community. It involves using resources effectively to meet the intended goals with minimal waste, allocating resources in a manner that is fair to all those who need them and that is sensitive to broader questions of justice in society. Stewardship also requires ensuring the long-term sustainability of the resources and clearly accounting for the decisions made about the use of the resources, including the value judgments that resource decisions are based on.

### Support for Physicians and Staff

Recognizing the integrity, the commitment and the meaning of work of the staff and leadership within the organization and supporting the staff and leadership to help make the work experience an integral part of a meaningful life. All staff has a tremendous stake in the experience of health care. We often spend more time with our colleagues than our families, we derive much of our self-worth from our vocations, and our professional experiences both offer us the ability to serve our community and derive meaning in our lives from this productive function. Conversely, because of the intimate nature of working in health care teams to serve vulnerable populations, we also have the potential to do much harm to our colleagues and our residents and to be harmed by our professional experiences. Many of us are also reliant on our employers for our livelihoods and are in a vulnerable position as a result. With so much on the line for all of us, it is important for the needs of the care giving community to be attended to by the organization – though not necessarily by those who are more vulnerable than ourselves – our residents and their supports.

### Timeliness

Making efficient use of time and responding to requests within a reasonable period after receiving it.

### Transparency (also known as publicity)

Exposing the process and rationale of decision-making for viewing and comment by others in a full, accurate and timely manner.

### Trust

Creating a safe, non-threatening environment where people can build relationships with people whom they can trust will treat them with integrity – that is, according to the values of PHC Residential Care. Central to any trusting relationship is honesty, open communication and transparency. To trust someone one needs to know that they will not be lied to or deceived and that one will be forthcoming with important relevant information in a manner that is respectful to the relationship.

### Unconditional Positive Regard

Fundamental respect for other people, a recognition that, whatever the differences of education, function, position, or opinion on a given issue, all are basically equal as human beings, deserving both recognition and respect. This basic respect grounds human interaction on all levels. In case of doubt, it trumps all other considerations.