

**Case Studies in Canadian Health Policy  
and Management, 2nd edition**

**Volume 2: Teaching Notes**

Edited by  
Raisa B. Deber  
with  
Catherine L. Mah

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Edited by Raisa B. Deber, with Catherine L. Mah

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## **Dedication**

This book is dedicated to all of the students who took and contributed to Raissa Deber's case studies course.



# **Case Studies in Canadian Health Policy and Management, 2nd edition Volume 2: Teaching Notes**

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Catherine L. Mah*

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<i>Raisa B. Deber</i>	
<p>In analyzing these case studies, a number of concepts may be helpful. To avoid undue repetition, this chapter briefly describes key concepts that recur in multiple cases. Although it could be read as a unified work, it is primarily designed to allow the reader to dip into these “theory bits.” Accordingly, we have not only cross-referenced concepts within Chapter 1, but also sought to cross-reference concepts between Chapter 1 and the cases by noting in each case the sections of Chapter 1 that might be particularly applicable. Chapter 1 in this volume of teaching notes also includes a listing of which cases (designated by chapter number) particularly focus on each of the specific theory bits.</p>	
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<p>In the spring and summer of 1999, more than 200 people of Tibetan descent crossed the New York-Ontario border into Canada and asked for refugee status. Five of the Tibetans were found to have active pulmonary tuberculosis (TB), a contagious disease, with the infecting bacteria resistant to all of the front-line medications initially used to treat TB. Media coverage on radio, national newspapers, and television ensued, much portraying the Tibetan situation as an example of how the Canadian immigration system was flawed, and was potentially putting Canadians at risk of contracting a deadly disease.</p> <p>This case addresses several policy issues, including: screening for communicable diseases, immigration policy, risk perception, and federal-provincial relations.</p>	
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*Nurlan Algashov, Patricia Baranek, Sherry Biscope, Kathryn Clarke, Mark Dobrow, Asmita Gillani, Irene Koo, Catherine L. Mah, Brandy McKenna, Michèle Parent, Miriam Alton Scharf, Shahzad Siddiqui, Louise Signal, Rachel Wortzman, and Raisa B. Deber*

What is health? How can government policy help to improve the health of a population?

This case addresses several policy issues, including: the determinants of health, the concept and implementation of healthy public policy, the role of health indicators, framing, public/private roles and responsibilities, policy instruments, and the roles of state/market.

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*Katerina Gapanenko, Catherine L. Mah, Shaheena Mukhi, David Rudoler, and Raisa B. Deber*

Rising levels of obesity have led to increasing concern that the next generation will be less healthy than their parents. The implications for health status, and health expenditures, have led to calls for remedial action. What are the alternatives, and who should be responsible for enacting them?

This case, a companion to Chapter 3 (Making Canadians Healthier), addresses several policy issues, including: the determinants of health, the concept and implementation of healthy public policy, framing, public/private roles and responsibilities, policy instruments, and the roles of state/market.

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*Brenda Gamble, Nancy Kraetschmer, Kenneth Cheak Kwan Lam, Catherine L. Mah, Caroline Rafferty, and Raisa B. Deber*

The small town of Walkerton, Ontario, earned unwanted prominence when an outbreak of water-borne disease between May and June 2000 left at least seven people dead and hundreds ill. In an effort to discover what went wrong, the provincial government set up a public judicial inquiry, under the leadership of Justice Dennis O'Connor. It was given a two-part mandate: to inquire into the circumstances that caused the illness (related to the presence of *E. coli* bacteria in the town's water supply), and to focus on the issues relating to the future safety of drinking water in Ontario.

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*Helen Looker, David Reeleder, and Raisa B. Deber*

In the summer of 2002, Ontario and Quebec experienced an epidemic of West Nile virus, associated with bites from mosquitoes. The public became very concerned that they were at risk of infection, and that the West Nile virus could be transmitted through the blood supply. To avoid recurrence of experiences with blood-borne transmission of human immunodeficiency virus (HIV) and hepatitis C, Canadian and US blood systems pushed for the development and implementation of a costly nucleic acid amplification testing (NAT) program to screen potential blood donors for West Nile virus.

This case addresses several policy issues, including: role of evidence, framing of issues, screening, policy trade-offs, cost-effectiveness analysis, ethics (precautionary principle), and federal-provincial roles and responsibilities.

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This case addresses several policy issues, including: public health, public goods, intergovernmental relations, ethical issues, privacy, and globalization.

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Health care is delivered by people; to operate effectively and safely, hospital units must be staffed by qualified, competent individuals. What options are available to a nurse manager and the hospital where she works to ensure that staff is available at all times to cover a hospital nursing unit?

This case addresses several policy issues, including: health human resources (HHR) shortages/surpluses, and computing the costs and consequences of alternatives, including implications for patient continuity of care and safety, and for staff nurse satisfaction and morale.

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A series of newspaper articles described the experiences of health care professionals who had immigrated to Ontario intending to work in their field, only to find the way blocked. How should foreign-trained professionals be handled? How many professionals were needed, and what was the fairest way to proceed?

This case addresses several policy issues, including: health human resources planning, professional self-regulation, framing, policy instruments, the impact of payment mechanisms, interest groups, and managing trade-offs across policy goals (including equity and efficiency).

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Over the past several decades in Canada, academics, health professionals, and provincial and national commissions have indicated that reform of primary care is key to sustaining a high-performing health care system. Yet despite considerable investment, primary care reform has proven difficult to achieve. What are the implications of different ways of organizing and financing primary care, and why has reform proved to be so difficult?

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*Laurie Bourne, Rachna Chaudhary, David Ford, Olivia Hagemeyer, Christopher J. Longo, Elaine Meertens, and Raisa B. Deber*

How much is it worth paying for how much benefit? Both practical (e.g., what does it mean to say a treatment works) and ethical issues have become particularly pronounced in dealing with new pharmaceutical treatments, such as the use of Avastin for people with colorectal cancer.

This case addresses several policy issues, including: cost-effectiveness analysis and the role of technology assessment, resource allocation ethics and rationing, the role of patients in decision making, and the implications of the public-private mix, with a focus on pharmaceutical pricing.

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*John Blake, Daniel Bolland, Ian Dawe, Brenda Gamble, Gunita Mitera, Natalie (Wajs) Rashkovan, Somayeh Sadat, Kenneth Van Wyk, and Raisa B. Deber*

People with cancer may be treated with various combinations of surgery, radiation therapy, and chemotherapy. Radiotherapy cannot be administered in every hospital; it requires equipment and skilled technical staff. One such specialized hospital, the Princess Margaret Hospital (PMH) in Toronto, found itself faced with a growing wait list problem in its radiotherapy department. What should it do?

This case addresses several policy issues, including: queuing theory, wait lists and how to manage them, human resources planning, payment mechanisms and incentives, and the ethics of rationing.

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Insurance cannot cover everything, and deciding what should (and should not) be included is not simple. In 1993, the government of Ontario had asked an arm's length panel to examine currently funded services that were deemed "unnecessary or of questionable medical benefit" so that they could be delisted from the provincial health insurance plan's schedule of benefits. Among the procedures de-insured was in vitro fertilization (IVF) for all infertility



diagnoses other than women with bilateral fallopian tube blockage. The technology has since improved, leading to calls to revisit the decision.

This case addresses several policy issues, including: priority setting and rationing (including the ethical issues involved), interest groups, and the role of the media.

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In 1992, Canada passed Bill C-91, which amended the *Patent Act* to extend the period of patent exclusivity for new pharmaceuticals in Canada from 17 to 20 years and eliminate compulsory licensing. Bill C-91 pitted social goals (and the interests of those using and paying for drugs) against economic goals (and the interests of those developing and selling these products). Under continued international pressure to liberalize trade markets, standardize intellectual property protection, and encourage a knowledge-based economy, some now question whether these provisions should be revisited.

This case addresses several policy issues, including: policy goals, framing of issues, scope of conflict, pressure groups, and globalization. This case can also be taught as a role play exercise.

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*Chris Bonnett, Christopher J. Longo, Yeesha Poon, and Raisa B. Deber*

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This case addresses several policy issues, including: regulation, the role of the state, scope of conflict, interests, globalization, and framing. This case can also be taught as a role play exercise.

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*Paul Holyoke, Marie Balitbit, Lee Tasker, and Raisa B. Deber*

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This case addresses several policy issues, including: insurance and moral hazard, policy/governing instruments (including regulation), and coverage for services falling outside the *Canada Health Act* requirements.

**Chapter 18: Everybody Out of the Pool: Financing Health Expenditures through Medical Savings Accounts..... 151**

*Kenneth Cheak Kwan Lam, Mark Rovere, and Raisa B. Deber*

What is the best way to pay for health care? As health costs increase, governments are increasingly seeking ways of controlling costs while ensuring adequate levels of coverage. Economists have suggested that greater use of market mechanisms, including encouraging patients to choose among competing providers, could improve quality and curb costs. One proposal is for greater use of personal medical savings accounts.

This case addresses several policy issues, including: financing, insurance and moral hazard, policy goals, and justice.

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*Patricia Baranek, Jane-Anne Campbell, Kerry Kuluski, Christopher J. Longo, Frances Morton-Chang, Karen Spalding, Carolyn Steele Gray, Fern Teplitsky, Romy Joseph Thomas, Jillian Watkins, Anne Wojtak, and Raisa B. Deber*

What services should be given to people who need assistance to remain in their home, and who should pay for them? A series of home care models have been proposed. What should the government do?

This case addresses several policy issues, including: alternative ways of financing and delivering care, public and private roles, definitions of medical necessity, and the impact of interests on policymaking.

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*Jane-Anne Campbell, Heather Chappell, Joanne Greco, Jeff Hohenkerk, Joshua Kline, Shannon L. Sibbald, Karen Spalding, Fern Teplitsky, Anne Wojtak, and Raisa B. Deber*

The board of a Community Care Access Centre must decide how to use their home care resources. Their budget is already insufficient to meet all current demand. A group of parents of children with disabilities have requested increased support. The board has been asked to develop a framework for allocating their budget. This case can also be taught as a role play exercise.

This case addresses several policy issues, including: resource allocation ethics and street-level bureaucracy.

**Chapter 21: Shoot and Tell: Mandatory Gunshot Wound Reporting by Physicians ..... 175**

*Carrie-Lynn Haines, Julie Holmes, Paul Miller, Sharon Vanin, and Raisa B. Deber*

In September 2005, the *Mandatory Gunshot Wounds Reporting Act* was proclaimed in Ontario. It required public hospitals to report the name and location of anyone being treated for a gunshot wound. Representatives of health professions expressed concern that this might damage their duty to patients, while others wondered whether similar reporting requirements should apply to other violent injuries.

This case addresses several policy issues including: balancing societal needs for protection with patients’ right to privacy, the ethical basis of the physician-patient relationship, and framing of policy issues.

**Chapter 22: Dying to Die: Euthanasia and (Physician-) Assisted Suicide..... 181***Christopher A. Klinger, Joe Slack, and Raisa B. Deber*

What is a good death, and how does one balance individual preferences against societal values? What is the role of physicians? A number of highly publicized cases have highlighted the dilemmas and reignited the debate on euthanasia and (physician-) assisted suicide in Canada. What should the legislature, and the courts, do?

This case addresses several policy issues, including: roles of legislature/courts; scope of conflict; roles of interest groups and media; and ethical frameworks.

**Chapter 23: Screen Tests: Genetic Testing in the Nursery and the Workplace ..... 187***Yvonne Bombard, Marion Bryce, Joe T.R. Clarke, Céline Cressman, Rea Devakos, Daniel Farris, Daune MacGregor, Zahava R.S. Rosenberg-Yunger, Natasha Sharpe, and Raisa B. Deber*

Genetic testing is a powerful tool that can help identify individuals at high risk for disease and/or vulnerability to environmental chemical hazards. However, there are numerous individual and societal implications regarding when these tests should be required, who should have access to test results, and what can be done with the information. Two scenarios are presented: genetic screening in the context of reproductive decisions, and genetic testing for insurance and employment purposes.

This case addresses several policy issues, including: screening; insurance; and the ethical issues relating to individual vs. societal rights, including issues of autonomy, privacy, and the risk of discrimination on the basis of genetic test results.

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## Acknowledgments

Writing this case book has been a complex exercise, spanning many years. We would like to express our appreciation for the many people who helped.

First, we would like to thank the many students who took Case Studies in Canadian Health Policy over the years, and helped write, edit, and clarify what was necessary to make these cases work in a classroom setting. Locating the many contributors to these cases was an interesting challenge. In addition to Google and LinkedIn, we would like to thank Mariana Vardaei, Christina Lopez, Tina Smith, Sue VanderBent, and the Society of Graduates in Health Policy, Management and Evaluation; we also thank the few students we could not locate who had contributed to early versions of some cases, but were not involved in writing the final revised versions.

In their roles as valuable colleagues and friends, Wendy Armstrong, Jan Barnsley, Andrea Baumann, Ahmed Bayoumi, John Blake, Ivy Bourgeault, Adalsteinn Brown, Tamara Brown, Mike Carter, Tony Culyer, Frieda Daniels, Gail Donner, Rick Fisher, Virginia Flintoft, Paul Froese, Brenda Gamble, Vivek Goel, Jillian Clare Kohler, Audrey Laporte, Chris Longo, Fiona Miller, Barbara Mintzes, Bill Ness-Jack, Dorothy Pringle, Michael Rachlis, Brad Sinclair, Cyra Sethna, John Stager, Yves Talbot, Ross Upshur, Michael Villeneuve, Frank Wagner, and Paul Williams also provided superb insight into those cases they were kind enough to review. Kanecy Onate, Christine Day, and Tim Walker provided essential support in editing and formatting cases, locating bibliographic items, and otherwise helping make these cases coherent. We also appreciate the help of Eric Carlson, Doug Richmond, Virgil Duff, and the staff at the University of Toronto Press.

In addition to their roles as loving family members, Charles Deber, Jonathan Deber and Karen Dawson, and Guy Schnitzler provided editorial assistance and unflinching support.

Raisa B. Deber and Catherine L. Mah, Toronto



## **Introduction**

This volume contains teaching notes for the cases in Case Studies in Canadian Health Policy and Management, 2<sup>nd</sup> edition. Note that each case has been extensively revised to try to ensure it is clear and accurate, up to date, and valuable to non-experts. As the list of authors makes clear, each case has benefited from the efforts of the many students who helped write and modify the cases.

We have tried to balance the need to cite our sources with the need to keep reading lists under control. As academics, we apologize for erring on the side of completeness. For more information on how to use the teaching notes, see Chapter 1 in this volume (volume 2).





## **Chapter 1: Teaching Notes**

### **Concepts for the Policy Analyst**

*Raisa B. Deber*

This volume of teaching notes is designed to facilitate class discussion of the cases included in Volume 1, the accompanying case studies book. Each of the teaching notes in Volume 2 includes the outcome, along with a brief discussion of various concepts that may be helpful in discussing the suggested questions. (In many cases, there are no single correct answers). Note that certain concepts recur in multiple cases; to avoid repetition, those topics are briefly described in Chapter 1 (Concepts for the Policy Analyst) of the case book. This volume of teaching notes briefly discusses how the instructor might apply selected concepts.

Because the cases are designed to be “rich”, the instructors may decide which points they wish to emphasize. Different classes may wish to stress different elements. The instructors may find that new elements and questions may emerge which we have not included in these teaching notes. For example, Chapter 2 (Danger at the Gates) was initially designed to focus on screening policy and federal/provincial/local relations. However, during the class discussion one year, we realized that it could also be used to illustrate risk perception. The cases have been designed to lend themselves to relatively open discussion that may not always follow a linear path. Should the instructor wish, some cases (particularly chapters 15, 16 and 20) also lend themselves to be taught as a role play exercise, where different students will take different parts.

The approach that Deber has used in teaching these cases is to emphasize student-directed learning rather than lectures. Indeed, rather than pre-determine which cases will be taught that year, we hold a pre-class session in which the students decide which cases they are interested in analyzing (which includes provision for the development of new cases), as well as which students (or groups of students) will facilitate/present each case discussion. The cases are then distributed/posted to the full class. To ensure helpful discussion, all class members are responsible for having read the case(s) being presented before they come to class, and having thought about the suggested questions. The presenter(s), and only the presenters, also receive a copy of the teaching notes for their case at that time. We have found that one helpful approach to teaching these case studies is to ask those responsible for presenting the case to prepare a draft agenda. This requires the presenter(s) to determine what key points they wish to ensure are covered and to be conversant with the relevant “theory bits”. We then ask the presenter(s) to prepare a list of possible discussion points, often in the form of a check list to enable discussion to be relatively free flowing within a general structure. The draft agenda is then refined through a meeting with the professor.

We usually begin the class discussion by asking class members to elicit a summary of the events of the case. We then move to discussion, trying to ensure that the key points emerge (leading questions can be helpful). We end with a wrap up, which may include going around the class and asking what each member would do (sometimes tallying the number selecting each alternative on the blackboard). The presenter(s) may also be armed with brief handouts to cover key “theory bits” and to pass these out as the relevant concepts arise in discussion. The agenda and/or teaching notes are subsequently made available to the full class. It is striking how often a seemingly free-flowing, albeit engaging, discussion proves to have covered all of the key points!

This is an example of the agenda we have used for chapter 2, Danger at the Gates.

### **Agenda: Danger at the Gates**

1. Elicit summary of events
2. Discussion points (to be checked off as they are raised by class):
  - What were the possible alternatives? Strengths/weaknesses
  - Characteristics of TB vs. other infectious diseases (e.g., AIDS, flu)
    - How infectious?
    - How deadly (and how to define deadly)?
    - Who is at risk?
  - Jurisdiction (fed/prov/local)
  - Civil rights issues
  - Justification for screening
    - Are these criteria appropriate? What values are assumed?
  - Risk assessment
  - Role of media
    - When is something newsworthy?
    - Did the public even notice this issue?

No later than 30 minutes prior to end of class:

Elicit preferred options and why

No later than 10 minutes prior to end of class:

Debrief. Hand out teaching notes. Summarize.

If desired, brief handouts can be prepared for key theory bits (e.g., issues in screening; risk perception, etc.)

Note that, to avoid repetition (and to give some background theory to the students), basic information (including selected references) about many basic concepts are included in Chapter 1 (Concepts for the Policy Analyst) in Volume 1 of the case book; these are then drawn upon in the teaching notes in Volume 2. For example, the discussion of screening policy in Chapter 2 could draw on Chapter 1, section 8.2, which also includes information about the criteria for screening (section 8.2.1), about how one might assess screening tests (section 8.2.2), and about how prevalence influences test performance (section 8.2.3). This information could also be useful for other cases (particularly, Chapters 6, 7 and 23). The case-specific information (e.g., how TB compares to HIV/AIDS and influenza) is not likely to be needed for other cases, and so it is included in the teaching notes to Chapter 2 rather than in Chapter 1. Similarly, overall information about federalism in Canada is in Chapter 1 (section 2.2.1), with the more case specific information given in the case and/or its teaching note. We have also tried to keep the list of references in both the case and the teaching notes both manageable and useful to those not already knowledgeable about particular topics (which includes trying not to repeat references given for particular cases in Volume 1 in the teaching notes for that case unless they are specifically cited). We have also referenced (and checked) potentially useful websites, recognizing that items may move over time.

Potential agenda items for the other cases can be gleaned from the questions for discussion in the case, and in the teaching notes.

Should the instructor wish to concentrate on various theories, the following indicates which cases specifically refer to each set of concepts discussed in Chapter 1 of the case book, where cases are referred to by chapter number (e.g., #2 denotes Chapter 2, *Danger at the Gates*). Note that some of the key concepts are not specifically referenced in particular chapters, but might still be helpful for the class discussion.

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    - 8.2.3 The Role of Prevalence (#2, #7, #23)
  - 8.3 Heuristics and Biases in Decision making
    - 8.3.1 Prospect Theory
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## **Chapter 2: Teaching Notes**

### **Danger at the Gates? Screening for Tuberculosis in Immigrants and Refugees**

*Michael Gardam, Marisa Creatore, and Raisa B. Deber*

#### **Outcome**

Following the realization that several recent refugees were suffering from active multidrug resistant tuberculosis (MDR-TB), Toronto Public Health developed a plan for the rapid triage and tuberculosis screening of all refugee applicants claiming Tibetan ancestry. This involved two changes from normal procedures. First, rather than rely on the claimants to present for their medical examination within 60 days of arrival, they would be identified at the border and bused to immigration specialists in Toronto. Second, the chest radiograph usually done (which would pick up active contagious disease) would be supplemented by a tuberculin skin test (which would also pick up latent disease, as well as other potential exposures). The triage process was complicated by the fact that Immigration officials at the border crossing stations initially refused to process the applications of Tibetan claimants once they realized the potential for infectious tuberculosis, although they eventually did agree to process them.

Over the summer of 1999, 118 Tibetans, including both some of the new refugee claimants and some members of the existing Toronto Tibetan community, were screened for active tuberculosis as well as latent infection. Overall, 92% were indeed found to be infected with tuberculosis (i.e., tuberculin skin test positive and/or abnormal chest radiograph). Only 18 had a prior history of being treated for active TB and 2 additional cases of active tuberculosis were identified. The rest, who were skin test positive but who did not have any evidence of active disease, were offered isoniazid therapy for 6 to 9 months.

Through this heightened screening process, public health officials believed that a potentially dangerous health crisis had been averted. Officials also stated that the process ran relatively smoothly due to cooperation between public health, border officials, and the Toronto Tibetan community. Without this cooperation, officials believed that the majority of cases would not have been detected unless the claimants had sought medical attention on their own accord.

Public health officials were quick to point out that while the degree of tuberculosis infection in the Tibetans they had tested was extremely high, many other cultural groups with potentially high rates of tuberculosis enter Toronto each year. Although the Tibetan crisis was detected and averted, most cases of tuberculosis in foreign-born individuals are not picked up through screening. Hence, while the Tibetan crisis was highly publicized, it was probably less of a threat to public health than those cases that go undetected.

One policy change resulting from this experience was Ontario's creation of the Tuberculosis Diagnostic and Treatment Services for Uninsured Persons (TB-UP). As noted in the case, Ontario had used the portability provisions of the *Canada Health Act* (CHA) which allowed them to impose a three-month waiting period before new legal residents of the province were eligible for provincially-funded hospital and physician services (see Chapter 1, section 7.2, *Canada Health Act*). This meant a further delay for refugees, whose three-month waiting time for eligibility would start only after they became legal residents. TB-UP partially filled that gap and provided immediate OHIP-like coverage, but specifically and only for TB diagnosis and treatment for those otherwise uninsured persons. The goal was to ensure that treatment delays

would not put others at risk. However, it only covered outpatient care, and only once someone was enrolled in TB-UP.

In March, 2011, Toronto Public Health urged the provincial government to eliminate the 3-month waiting period, and make all newly landed immigrants immediately eligible for OHIP. Despite the TB-UP program, they argued that new immigrants remained reluctant to seek medical treatment for fear of not being able to pay the bills; they specifically mentioned tuberculosis and measles as conditions being undertreated. They noted that getting the initial assessment and chest X-ray needed to diagnose TB could cost several hundred dollars out-of-pocket, and that hospitalization, if needed, could cost patients up to \$70,000. Private medical insurance was not helpful, since TB would be deemed a pre-existing condition and therefore would not have been covered (see Chapter 1, section 5.9, Insurance, Elasticity and Moral Hazard). The report also noted that Toronto saw about 300 TB cases every year, with over 90% being from people born outside the country. Although relatively few cases occurred among immigrants during the 3 month OHIP waiting period, Toronto Public Health argued that even this small number constituted an unacceptable public health risk.

In 2012, the federal government announced that it would significantly reduce health coverage for refugee claimants. It eliminated the Interim Federal Health Program (thus eliminating all supplemental benefits, including for medications, dental care, vision care, etc.) and denied any coverage to those with rejected refugee claims unless their conditions were seen to pose a risk to public health and safety. The policy has evoked considerable dissent from provincial governments (who may have to pick up many of these costs) and from health providers, including many national health care organizations representing physicians, nurses, pharmacists, etc. In theory, TB care would not be affected, since it would be classified as posing a risk to public health, but the necessary diagnostic procedures might not so qualify.

### **Possible Points for Discussion:**

#### ***1. What are the possible policy alternatives for TB screening? Discuss their strengths and weaknesses.***

The possible tests available at the time of the case are described in Appendix C of the case. Note, however, that in December 2010, the WHO endorsed a new rapid TB test, a fully automated NAAT (nucleic acid amplification test), which would allow results “while you wait”, and has been negotiating with the manufacturer for reduced pricing in low- and middle-income countries where TB is endemic. At the time of writing, however, most testing still used the tuberculin skin test plus chest radiograph, or sputum tests.

Regardless of which tests were used, the main policy options would include:

a. *Test all* potential immigrants. This option would dramatically increase the detection rate of applicants with latent disease (i.e., those with positive tuberculin skin tests and negative chest radiographs) while still detecting those with active contagious disease (i.e., those who had positive chest radiographs). The testing could either be performed by the Designated Medical Practitioner (DMP) during the initial medical examination in the country of origin, or by the local Public Health Unit after arrival in Canada; the class discussion may also wish to address the policy implications of who performs the testing. (Would there be a potential for individuals with disease to fraudulently purchase negative test results?) The “test all” option has a higher risk of picking up false positives when used in populations at relatively low risk of being infected with

*M. tuberculosis*. As will be noted below, screening low prevalence populations can also be extremely costly.

b. *Test some* (high risk only). As the publications on the World Health Organization website show, there is a large difference in TB incidence between different regions of the world; in addition, certain age and sex groups are at greater risk than other groups. A risk score could be developed for various immigrant profiles and certain groups could be identified as requiring screening. This strategy would theoretically detect the majority of active and inactive cases while limiting the number of tests performed. However, a policy of requiring such testing only for some countries may be seen as discriminatory. It may miss cases, since low risk does not mean zero risk. Indeed, as shown on the Health Canada and Public Health Agency of Canada websites, some Canadian-born populations are also at relatively high risk. Appendix A of the case includes some information about who was most at risk in Canada.

c. *Do not screen*; focus on treating active cases as they appear and tracking down contacts of active cases to offer them treatment (known as “contact tracing”). This strategy would focus public health efforts on the early diagnosis and treatment of active cases of tuberculosis and the close follow-up of their high-risk contacts. The identification of contacts is considered an important means of preventing the development of active disease or at least identifying new cases early on before there is significant transmission to others.

These three alternatives are obviously not the only possible solutions to the tuberculosis surveillance dilemma. They vary in the trade-offs between avoiding false positives and avoiding false negatives. As noted in Chapter 1, section 8.2 (Screening), drawing the line between false positives and false negatives depends on the consequences of various types of error. For example, a high rate of false positives means that most of those testing positive will not have disease, which imposes costs (and potential harm) on those without disease as well as on the health care system.

## ***2. How much of a public health risk does TB pose? How does it compare with other communicable diseases (e.g., influenza, or HIV/AIDS)?***

Chapter 1, section 8.3.2 (Risk Perception) discusses how risk is perceived. Note that this case involves the potential for unknown, involuntary exposure to a serious disease, which the literature suggests would inflate perception of risk.

The epidemiological and clinical features of TB are summarized in the appendix material to the case. The class may want to consider the similarities and differences between TB and other infectious diseases on such dimensions as: how is it transmitted, how infectious is it, how common is it, who is at risk, how severe is it, and whether it can be treated. To facilitate this discussion, a somewhat oversimplified comparison among TB, influenza, and HIV/AIDS on these dimensions follows:

### ***How is it transmitted? How infectious is it?***

TB is an airborne transmitted disease (i.e., infection occurs by inhaling microscopic infectious particles). The risk of transmission is dependent upon many factors, including infectiousness of the index case, duration of exposure and proximity to the index case, and the characteristics of the ventilation in the space where the exposure occurs. Fortunately, it is very unusual for tuberculosis to be transmitted during brief contact; typically exposure over hours is required.

Influenza can be highly contagious. It is likely transmitted via a few different routes, including contact with contaminated surfaces followed by self-inoculation of the mucous membranes and direct inoculation of the mucous membranes by large droplets resulting from the source patient coughing or sneezing. There is also a theoretical risk of airborne transmission, although the lack of any evidence supporting transmission over long distances suggests that this route is rare, if it exists.

HIV/AIDS requires contact with blood or other bodily fluids, and hence is usually spread through sexual contact or blood. In the absence of such exposure, risk of transmission is very low.

*How common is it? Who is at risk?*

TB is a rare disease in Canada, although it is very common in many countries. In Canada, the annual incidence of active disease was 2-6 cases per 100,000 population (about the same as the rate of such non-infectious conditions as thyroid cancer or aortic aneurysms). If an individual does become infected with TB, the lifetime risk for an infected but otherwise healthy person of developing active disease is 5-10%; however most of this risk occurs in the first few years after infection. A 0.1% annual risk of reactivation is often cited. Therefore, although TB can be a very serious disease, the actual risk of infection to the general Canadian public is quite low; if a person is infected but otherwise healthy, their risk of developing active disease is also quite low. However, this risk is not uniform; there are certain population groups with underlying risk factors who are at greater risk of reactivation and developing active disease. For example, if one also has HIV/AIDS, the annual risk of reactivation has been estimated at 10% per year, which makes the relative risk of developing active TB 170-fold higher than for someone who was otherwise healthy. Recent immigrants, Aboriginal people and the homeless all have higher rates of TB than the Canadian average. The risk of TB within certain immigrant communities may be relatively high and there was some concern that the rates of MDR-TB in these populations were increasing. The spread of TB by infectious, recent immigrants would be considered fairly risky by the general public; however, research suggests that transmission of TB from immigrants to non-immigrants is rare (since those at highest risk are the household contacts of infected persons).

Influenza is relatively common. Most infected people recover within one to two weeks without requiring medical treatment. However, in the very young, the elderly, and those with other serious medical conditions, infection can lead to severe complications, including pneumonia and death. The influenza virus is transmitted easily from person to person via droplets and small particles produced when infected people cough or sneeze. Influenza tends to spread rapidly in seasonal epidemics.

HIV/AIDS is relatively uncommon. The Public Health Agency of Canada estimated that, at the end of 2008, there were approximately 65,000 people living with HIV (including AIDS) in Canada, of whom 26% were unaware of their infection. The number of people newly infected with HIV in Canada in 2008 was estimated to be between 2,300 and 4,300. Populations at greatest risk tended to be IV drug users, people having unprotected sex with HIV positive individuals, recipients of contaminated blood products, and infants exposed by an infected mother.

*How severe is it? Can it be treated?*



Untreated, active TB is often fatal, and multi-drug resistant TB can, in extreme cases, prove untreatable. In general, however, TB is a treatable disease even though the treatment itself may be unpleasant and associated with its own health risks. Because TB is a treatable disease, the potential threat to public health can in theory be eliminated if a person is identified as having active or latent disease and accepts treatment. In this scenario, immigration screening is not just a tool to identify persons for exclusion from the country, but a method to ensure appropriate treatment is provided for those that are allowed entry. TB thus differs from some other conditions, for which no cure is yet available. Note that where there is not yet a cure, the major justification for screening is often on public health grounds, where case identification may benefit others, but not necessarily the infected individuals.

Influenza is a viral infection. Infection usually lasts for about a week. Symptoms include high fever, aching muscles, headache, malaise, cough, sore throat and rhinitis. Influenza can also, rarely, be fatal, but is generally mild. Vaccines are also available, although due to rapid mutations of the influenza virus, their effectiveness varies.

HIV/AIDS is very serious with essentially a 100% fatality rate if untreated. With the advent of highly active antiretroviral therapy, survival is now dramatically improved and HIV/AIDS has evolved into more of a chronic disease. (Note, however, that those with HIV/AIDS are also at higher risk from TB.)

***3. Discuss when screening is justified and how it should be implemented. Is screening for latent TB disease among recent immigrants justified? Among other Canadians judged to be at higher risk? Among all Canadians?***

Screening is not the same as testing. Testing can be used for those likely to have a particular condition to confirm a diagnosis, and/or assist in monitoring, prophylaxis or treatment, whereas screening refers to using tests in a wider population who do not have any obvious risk factors for that condition. Chapter 1, section 8.2 (Screening) discusses test characteristics, including sensitivity (defined as the percentage of those with disease who test positive) and specificity (defined as the percentage of those without disease who test negative). Note that the value of screening depends heavily upon prevalence (the proportion of people in the entire population being tested who are found to have a particular condition at a certain point in time). What happens when prevalence is low?

The instructor may wish to ask the class whether they think that TB screening meets the criteria noted in Chapter 1, section 8.2.1 (Criteria for Screening). (To place the responses in context, the same questions could also be asked for HIV/AIDS, and influenza.)

1. The condition sought is an important health problem.
2. There is an accepted treatment for patients with recognized disease.
3. Facilities for diagnosis and treatment are available.
4. There is a recognizable latent or early symptomatic stage.
5. There is a suitable test or examination.
6. The test is acceptable to the population.
7. The natural history of the condition, including development from latent to declared disease, is adequately understood.
8. There is an agreed policy on whom to treat as patients.
9. The cost of case-finding (including diagnosis and treatment of patients diagnosed) is economically balanced in relation to possible expenditure on medical care as a whole.

10. Case finding is a continuing process and not a “once and for all” project (Wilson & Jungner, 1968).

In general, most conclude that screening for active TB more or less meets criteria 1 through 8. The cost-effectiveness of various strategies, however, depends on the strategy used. For example, criterion 10 is not met since immigration screening is a “one-off” process for each individual immigrant. For latent disease, it is debatable whether criteria 1, 5 and 8 through 10 are met. The instructor may also wish to ask the class what the underlying assumptions of these criteria are, and whether they are appropriate. In general, they justify screening entirely in terms of benefit to the individual affected. However, in cases of communicable disease, there may also be a rationale for identifying cases even if they cannot be treated, in order to protect others. (This was a heated debate in the early days of HIV/AIDS, in terms of whether benefit to others who might be at risk would justify screening, even if the individuals affected could not yet be treated and hence would not personally benefit and might be harmed.)

Another debate concerns the consequences of false positives and false negatives. In the case of a serious, infectious disease such as TB, the repercussions of not identifying active cases may be increased transmission of disease in the community; accordingly, a test that has high sensitivity and generates few false negatives is needed. For other conditions, the cost (both financial and clinical) of following up false positives may be high, in which case the goal is finding a test with high specificity. Individuals testing positive may be stigmatized, and tests and treatments carry their own risks. Under these circumstances, tests that identify many false positives may do more harm than good. (This trade-off lies at the heart of current debates about the value of screening for prostate cancer and breast cancer, where the damage to the false positives in terms of unnecessary tests and treatments has been considerable.) Ideally, tests would have both high sensitivity and high specificity, although this is not always achievable.

The tuberculin skin test (Mantoux test, or TST) has been used for almost a century to diagnose latent tuberculosis infection. The sensitivity of the test is believed to be 97%, but the specificity is lower. In particular, false positive reactions can occur in individuals who have received the BCG vaccine, if they received the vaccine when they were greater than 1 year old. As a result, when this test is used in BCG-vaccinated populations at low risk for tuberculosis infection, the positive predictive value of testing positive is less than 50%. Conversely, the sensitivity of this test suffers in populations with conditions that result in impaired cellular immunity, including people with HIV/AIDS, chronic renal failure, or those receiving immunosuppressive medications for such conditions as organ or bone marrow transplants.

Recently, two interferon gamma release assays for the diagnosis of latent tuberculosis infection have been licensed in Canada. In general, these blood tests are believed to be as sensitive as the tuberculin skin test but also have improved specificity because they do not react to antigens present in the BCG vaccine. They do, however, have similar issues with impaired sensitivity in populations with weakened cellular immune systems. These tests have the advantage of requiring only one visit (rather than two for the TST); however, they were considerably more expensive than the TST and at the time of writing were not yet widely available in Canada.

Using the information about screening tests in Chapter 1, sections 8.2.2, (Assessing Screening Tests) and 8.2.3 (The Role of Prevalence), the class may wish to work through the following example:

In the year 2000, India had a TB prevalence rate of 346 per 100,000. If the same rate held for the 18,290 people who had immigrated to Canada from India in 2002, we would therefore

expect approximately 63 cases of active tuberculosis. Assuming that the chest X-ray has a sensitivity of 75% and a specificity of 99% (approximating figures found in the literature) (Toman, 1981), of the 63 “true” cases screened, 47 would be identified. Of the 18,227 people without disease, 182 would be incorrectly identified as having TB. Therefore, of the 229 people identified as having TB, only 20% actually would have disease; the remaining 80% of those identified as having TB would be false positives.

If the policy were implemented for countries that have lower prevalence rates than India, the predictive value and yield would be even lower. The class may wish to repeat the calculations, assuming that 10,000 were screened, but that the prevalence rates were the same as Sri Lanka (74 per 100,000). One might also wish to vary specificity (e.g., if only the skin test were used, specificity would drop from 99% to 90%). An additional wrinkle is that specificity is further reduced because people without TB who have received the BCG vaccination after the age of 1, or who were exposed to other mycobacterium, may still test positive. Given how common BCG vaccination is in many of the home countries from which immigrants come to Canada, it has been estimated that approximately 40% of all immigrants to Canada would have a positive skin test, many of whom would be false positives. That would translate into approximately 100,000 people testing positive annually. Presumably, those testing positive would be offered preventive therapy. Would people be given incentives to take medication? What are the ethical implications? Even if a large percentage did take the medications, this would mean that each year, tens of thousands of new arrivals, many of whom would be false positives, would require a 9 month supply of medication and monthly medical visits. One estimate was that approximately 30 people would have to undergo 9 months of isoniazid therapy to prevent 1 case of TB. Furthermore, approximately 0.11 to 0.2% (100 – 200 people) would develop significant side effects likely requiring hospitalization, and in the worst case scenario, might go on to require liver transplantation or possibly die (Menzies, 2003).

Thus, any large surveillance program involving preventive therapy would have such significant downstream effects on the healthcare system and on those with false positive test results that it would likely be impossible, and probably inappropriate, to implement. A more feasible solution might be to “screen some”, that is, identify and screen high risk groups. Presumably, the skin test in conjunction with a chest X-ray would capture the majority of active cases. The screen some option is also made more complex because applicants (especially refugee claimants) may enter Canada from a country other than their actual place of residence, which would make determination of the country of origin difficult in those cases. Finally, determining who needs to be screened based on country of origin may be considered as a form of discrimination, particularly if decisions are based on ethnicity rather than on objective risk assessment. Indeed, the risk of TB infection is affected not only by a person’s country of birth, but by where they have lived and visited.

Screening for latent infection is even less of an exact science. Public health experts argue that such screening would only be useful if the information obtained is acted upon; this has cost and logistical implications. As one example, note the comments in the case from the TB specialists about the absence of a system. How would information flow from whoever performed the screening tests (usually, a physician) to the local public health unit, and what would be done with the results?

The “screen none” alternative involves eliminating medical surveillance post-landing and focusing on identifying active cases and their close contacts who may be at risk of disease. Supporters of this policy alternative believed that the current method of medical surveillance is

so ineffective that stopping the process entirely would have little effect on case identification rates. This was based on the assumption that, due to the imperfections of the screening tools available at a population level, screening for latent disease would not result in significant public health advantages over waiting for a person to become ill and present to a physician. In addition to this passive screening technique, once cases were identified, public health authorities would employ *contract tracing* (contact and screen all persons who may have been exposed to the infected individual). Contact tracing is considered an important means of identifying new cases early on before there is significant transmission to others, as well as a means of preventing the development of active disease. Once identified, contacts would be screened by a tuberculin skin test and chest radiograph.

This “sit back and wait” option, even if it were as effective as more aggressive immigration screening, would be controversial. Canadians might have a difficult time accepting that there was no screening of immigrants at relatively high risk of becoming infectious. This option also assumes that persons will seek care when ill. There may be negative public health consequences if persons who arrived ill or became ill shortly after arrival were hesitant to contact the health care system for fear of jeopardizing their immigration application or refugee claim. Another possible problem with this option was the 3-month waiting period for health insurance eligibility in some provinces, including Ontario, which was seen to pose additional disincentives for ill persons to come forward until they were eligible for full insurance coverage. Indeed, as noted in the case, it was precisely this concern that led to the implementation of TB-UP (TB Uninsured Program), which paid for “reasonable” TB work up and treatment, including payments for physicians, tests, and medications, for those who were uninsured.

#### ***4. What are the goals of immigration policy? How should these be balanced?***

There is an ongoing dispute as to how to balance the various goals of immigration policy. Humanitarian concerns would indicate that Canada should admit those in danger of persecution in their home country. Others argue that the refugee claims process is being misused by those seeking to bypass the procedures for determining who can be admitted to Canada. This debate is largely based on values held, and as such there does not appear to be a “right answer”. There are also disputes as to who should pay for care, and for whom (see Chapter 1, section 3.2, Role of the State).

#### ***5. Discuss the roles and responsibilities of the various levels of government in controlling TB. Who is responsible for the health of recent immigrants? Is TB a local or a national problem?***

Note that there are few mechanisms for dealing with global public health issues (see Chapter 1, section 5.5, Globalization), although such international bodies as the World Health Organization do attempt to help jurisdictions work together. Even within national jurisdictions, coordination can be complex. As noted in Chapter 1, section 2.2.1 (Federalism in Canada), Section 95 of the *Constitution Act, 1867* provides that the Parliament of Canada and the provincial legislatures exercise concurrent legislative authority over immigration, while making federal legislation paramount in situations of conflict. Citizenship and Immigration Canada thus has responsibility for developing immigration policy, managing immigration levels, and facilitating and controlling the entry of immigrants, refugees and visitors to Canada. Citizenship and Immigration Canada also holds authority over the initial medical surveillance process for immigrants and refugee claimants under the *Immigration Act*, although at the time of writing federal government policy also gave a growing role to the provinces/territories in selecting

immigrants. However, once someone is admitted, they are free to move across provincial borders. Once the medical screening examination was completed, however, any additional testing or surveillance of the would-be immigrant became the responsibility of the provincial Ministry of Health in conjunction with the local public health units, since healthcare is a provincial responsibility under the *Constitution Act*. (However, refugee claimants who require medical care did remain at least partially the financial responsibility of the Federal government, at least until their claims were adjudicated.)

The primary infectious disease control role of immigration policy is to exclude or treat prior to arrival persons that may present a risk to public health or safety. This may include those who have active, infectious diseases, including tuberculosis, syphilis and in some cases, HIV. As noted in the case, given the low prevalence of TB in Canada, and the fact that many recent immigrants come from areas that have a relatively high incidence of TB, the majority of TB diagnoses in Canada are found in the foreign-born. In theory, an effective screening test prior to immigration could detect most TB cases. The immigration medical exam is meant to identify persons who have active disease; however, it does not effectively identify persons that have been infected but have latent disease.

The federal, provincial/territorial, and local levels of government all purport to value the protection of the health and well-being of Canadians, and readily concede that the threat of new immigrants and refugee claimants infecting Canadians with tuberculosis is a potential concern. Yet, when it comes down to determining who is primarily responsible for different components of the immigration surveillance process, there is substantial disagreement. Jurisdictional boundaries can also be used as an excuse for each level of government not to become involved in an issue that they would rather avoid. Inadequate social support or health infrastructure to address the needs of recent immigrants often has a significant impact on the local governments where they reside.

### ***6. Discuss the ethical issues involved in balancing control of infectious diseases with civil rights.***

As noted in Chapter 1, section 3.6 (Ethical Frameworks), most of medicine concerns itself with the rights of the individual; the principles of autonomy, beneficence, non-maleficence, and justice are often key. In the public health arena, in contrast, the well-being of the community is paramount and the rights of the community may come into conflict with those of the individual (see also Chapter 1, section 6.3.1, Public health). Indeed one group likely to be at comparatively high risk of infection could be health professionals (and others who work in or use hospitals).

A number of ethical issues might be discussed in class. The World Health Organization has published a brief factsheet looking at ethical issues in TB (World Health Organization, 2011). These include the extent to which it is acceptable to sacrifice individual rights to protect a wider community. In certain circumstances the control of an infectious disease benefits the non-exposed members of the community and not the infected person, particularly if no good treatment is yet available. Quarantine, enforced treatment and even screening itself may not be in the best interest of the infected person, but may be deemed justifiable by public health authorities. Similarly, what should be done if people do not wish to take TB preventive therapy? Would you force individuals to be treated? Is it appropriate to use coercive public health measures on people without active disease and thus not posing an immediate public health risk? Would you coerce them by making legal immigrant status conditional on successful completion of preventive treatment? Should this depend on the rate of TB in their country of origin?

Other ethical issues might involve definitions of *equity* (see Chapter 1, section 3.3.3. Equity). To what extent is it acceptable to treat potential immigrants differently from those already resident in Canada? Do citizens have different rights from non-citizens who are legal residents? From residents who did not legally enter the country? From non-immigrants such as students or tourists? From certain Canadian populations (including some living on First Nations reserves) with high rates of TB? There is additional variability in who must be screened. For example, at the present time, screening would not be recommended for the visitors, students and temporary workers entering Canada unless they come from designated countries and are staying in Canada for 6 months or more. The burden of being screened and forced to take treatment (and possibly deal with serious side-effects) is largely being placed on the shoulders of legal immigrants. Is this an equitable distribution of the risks and burdens of an intervention? Those with HIV infection tend to have high rates of false negative reactions to TB screening; would this imply that HIV status would have to be disclosed at the time of screening and communicated to those involved with the follow-up?

A related issue that is related to developing a mandatory screening and treatment program is that of *compliance*. As a result of feeling targeted by authorities, immigrants may seek to avoid contact with immigration and health authorities. A coercive policy may even act as a disincentive for those who are at greatest risk for TB to enter the country legally. This would result in worsening of the situation if illegal immigrants who then develop infectious disease are afraid to seek care.

How important is *cost-effectiveness* as a consideration (see Chapter 1, section 8.1, Economic Analysis: Cost-effectiveness)? If life has infinite value, then even a small benefit should be pursued. The precautionary principle (see Chapter 1, section 3.6.2, The Precautionary Principle) in effect argues that we should always assume the worst, and act to minimize risk. The economic concept of opportunity cost, however, would say otherwise; particularly if the resources used could generate higher benefits if used otherwise. How should policy makers factor in current and future risks and costs?

Particularly given the stigma and other adverse consequences of testing positive, there are likely to be major clashes between civil rights principles and public health concerns.

### **7. Discuss the role of the media.**

The class may also wish to discuss the role of the media (see Chapter 1, section 5.8, Role of Media), particularly with regard to setting and influencing policy agendas. Will the reactions be different for the general public, immigrant communities, politicians, and healthcare providers? Note that several elements of this story would make it be seen as newsworthy. However, it should be recognized that failure of the potential threat to materialize would make the story less newsworthy; over time, it would also no longer be new. It is also important to recognize that most of the public were probably unaware of this story. Policy makers could be influenced, however, by the potential for negative coverage (and negative public reaction) should TB have spread to the general population.

### **See also in Chapter 1:**

- 2.2.1 Federalism in Canada: *The Constitution Act, 1867*
- 3.2 Role of the State
- 3.3.3 Equity
- 3.4 Framing

- 3.6 Ethical Frameworks
  - 3.6.2 The Precautionary Principle
- 5.5 Globalization
- 5.8 Role of Media
- 5.9 Insurance, Elasticity and Moral Hazard
- 6.3.1 Public Health
- 7.2 *Canada Health Act*
- 8.1 Economic Analysis: Cost-effectiveness
- 8.2 Screening
  - 8.2.1 Criteria for Screening
  - 8.2.2 Assessing Screening Tests (test/truth)
  - 8.2.3 The role of Prevalence
- 8.3.2 Risk Perception

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[http://libdoc.who.int/php/WHO\\_PHP\\_34.pdf](http://libdoc.who.int/php/WHO_PHP_34.pdf)

### The following websites may also be helpful:

- Citizenship and Immigration Canada (<http://www.cic.gc.ca/english/index.asp>). Including:  
 Citizenship & Immigration Canada. (2013). *Annual report to Parliament on immigration, 2013*.  
<http://www.cic.gc.ca/english/resources/publications/annual-report-2013/index.asp>.
- Health Canada: Tuberculosis – Diseases and Conditions (<http://www.hc-sc.gc.ca/hc-ps/dc-ma/tuberculosis-eng.php>)

Public Health Agency of Canada (<http://www.phac-aspc.gc.ca/tbpc-latb/index-eng.php>)

Toronto Public Health (<http://www.toronto.ca/health/>). *Tuberculosis*  
(<http://www1.toronto.ca/wps/portal/contentonly?vgnextoid=07f85dc06f002410VgnVCM10000071d60f89RCRD&vgnextfmt=default>)

World Health Organization (<http://www.who.int/tb/en/>). Helpful publications include:

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## Chapter 3: Teaching Notes

### Making Canadians Healthier: Where Do We Start?

*Nurlan Algashov, Patricia Baranek, Sherry Biscope, Kathryn Clarke, Mark Dobrow, Asmita Gillani, Irene Koo, Catherine L. Mah, Brandy McKenna, Michèle Parent, Miriam Alton Scharf, Shahzad Siddiqui, Louise Signal, Rachel Wortzman, and Raisa B. Deber*

#### Outcome

For the most part, governments in Canada have not acted on the healthy public policy agenda; it has received far less attention in recent years than had previously been the case. Health policy has instead focused less on the determinants of health than on such priorities as shortening waiting lists for designated procedures (including several categories of elective surgery and diagnostic imaging). Income inequality has increased, and social support programs have tended to diminish, in part as a reaction to economic difficulties. In terms of public discourse, health promotion is often being defined rather narrowly, largely in terms of improving individual lifestyles (particularly smoking, obesity, and exercise). Some keep attempting to support an equity/determinants of health agenda, but it has received little public support.

As noted in Chapter 1, section 1 (What is Policy), policy involves “A set of interrelated decisions taken by a political actor or group of actors concerning the selection of goals and the means of achieving them within a specified situation where these decisions should, in principle, be within the power of these actors to achieve” (Jenkins, 1978). The concept of healthy public policy argues that these decisions should incorporate consideration of the implications for health (Milio, 1987). Others might argue that this is imperialistic, in that goals other than health are also valid. Healthy public policy can thus be a complex concept, often hard to understand and difficult to implement.

#### Possible Points for Discussion:

##### ***1. How would you define/measure health? How do the various definitions of health affect the potential policies you might recommend?***

As noted in the case, a number of reports have emphasized the social determinants of health; these include the 1974 Lalonde Report (Lalonde, 1974), the Alma Ata Declaration (World Health Organization, 1978), the Ottawa Charter for Health Promotion (World Health Organization, 1986), the Epp Report (Epp, 1986), the reports on the health of Canadians (Federal Provincial and Territorial Advisory Committee on Population Health, 1996, 1999), the Romanow Commission (Commission on the Future of Health Care in Canada, 2002), and the Senate report on health protection and promotion (Standing Senate Committee on Social Affairs Science and Technology, 2003). Why have they had so little traction?

As noted in Chapter 1, section 3.3.3 (Equity), the policy goal of equity has multiple meanings (Stone, 2002). Different definitions of equity can be associated with different beliefs about the appropriate way to distribute (or redistribute) wealth, power, and/or goods. The class may wish to discuss the various policy actions that would be needed to deal with the four health fields identified by the Lalonde Report (Lalonde, 1974). *Biology/genetic* problems would imply

the need for biomedical research; the *health system* would imply ensuring access to treatments once these are developed; *lifestyle* would imply a focus on individual behaviour; and *environment* would imply a focus on factors outside the health care system, including air and water quality, transportation, and urban planning. To the extent that inequalities in health are rooted in inequities in society (which is partially but not entirely the case), closing the health gap would imply giving a higher priority to the most vulnerable populations. The Ottawa Charter goes beyond this to focus on healthy societies, which in turn would require attention to shared values, including democracy and equity, that may in turn facilitate and advance the health and well-being of individuals and societies. Another element of this view is a stress on community action/community participation and enhancing community capacity (Mittelmark, 2001).

Consider the implications if one accepts this expansive 1988 World Health Organization (WHO) definition: “Healthy public policy is characterized by an explicit concern for health and equity in all areas of policy and by an accountability for health impact. The main aim of health public policy is to create a supportive environment to enable people to lead healthy lives. Such a policy makes health choices possible or easier for citizens. It makes social and physical environments health-enhancing. In the pursuit of healthy public policy, government sectors concerned with agriculture, trade, education, industry, and communications need to take into account health as an essential factor when formulating policy. These sectors should be accountable for the health consequences of their policy decisions. They should pay as much attention to health as to economic considerations” (World Health Organization, 1988).

Note that, if this view is accepted, everything is health. The definition includes equity and social justice, and has implications for tax policy, education, city planning, transportation, and a host of activities extending well beyond the usual mandate of ministries of health. This view also has a strong ideological element, which its opponents might term socialist. They may also argue that such a focus may neglect other important policy goals (e.g., economic development).

**2. Discuss the different indicators noted in Appendix B (including death rates, PYLL, and hospitalizations). What would each suggest as policy priorities? What might be omitted?**

Note that the different indicators can point to very different policy priorities.

If one focuses only on avoiding mortality, one would look at the causes of death. The leading causes of death are circulatory system diseases and cancer. However, these causes disproportionately affect those over 65. It should also be recognized that everyone dies at some point, so one could argue that one cannot “save” lives, but only prolong them. One might therefore want to focus on life expectancy, and increasing life years. This might call for focusing on potential years of life lost, or PYLL; however, this indicator tends to assign no value to years lived after a given cut-off. The largest “bang for the buck” using the PYLL metric would thus arise from reducing death rates among the young. In richer countries, including Canada, death rates among children tend to be very low (except for newborns, where the major causes of death in that group includes perinatal causes and congenital anomalies). Scrutiny of the tables included in the case reveals that unintentional injuries are the most common cause of death among those between ages 1 and 34 (although, fortunately, they still account for relatively few deaths). Suicide is one of the major causes of death for those between ages 10 and 44 (although one reason is that death rates in these age groups are otherwise quite low). Focusing on these indicators might place more attention on accidents, food/nutrition, and mental health, which did not emerge as central concerns when focusing purely on overall mortality. Hospitalization shows similar patterns to causes of death, but several conditions that cause morbidity but not as much

mortality emerge (particularly digestive system diseases, genitourinary diseases, and musculoskeletal diseases). If the desire is to reduce public expenditures, some attention might be paid to preventable hospitalizations (e.g., how might one reduce respiratory system diseases?).

Also note that the time frame for affecting health can be long, and results are not certain. Not everyone who smokes gets cancer, and the time between exposure and illness is often considerable. Politicians receive little reward from making changes whose impact will not be felt during their administration. There are also issues regarding what is considered to be a private matter, vs. what is a legitimate target for public intervention. Research reports point to the importance of distribution and disparity of income as important determinants of health. This data, however, is correlational rather than causative and does not address the etiology of ill health. Does income affect health status, or does health status influence income, or both? The relationship is still unclear. Certainly, people with disabilities may find it difficult to be able to work at some jobs, which may impair their ability to earn income.

A population health approach recognizes that any analysis of the health of the population must extend beyond an assessment of such traditional health status indicators as death, disease, and disability. A population health approach may establish indicators related to mental and social well-being, quality of life, life satisfaction, diet, poverty, housing, income, employment and working conditions, education and other factors known to influence health. These non-medical determinants of health may more likely be challenging to measure but are still potentially important. There is also a risk that certain indicators will not be chosen because they are difficult to measure, which in turn may skew policy/political agendas.

There have been several efforts to develop indicators that tap some of these non-medical determinants of health. For example, the Genuine Progress Index (GPI) is based on living standards, population health, how people use their time, community vitality, education and environmental quality. The Canadian Index of Wellbeing (CIW) is based on democratic engagement, community vitality, education, environment, healthy populations, leisure & culture, living standards and how people use their time (Health Council of Canada, 2011). All have different policy implications.

### ***3. Discuss framing as it applies to how the policy problem is defined.***

As noted in Chapter 1, section 4.3 (Scope of Conflict), Schattschneider argued that policy makers attempt to frame policy options in order to manage the scope of conflict, which affects who gets involved in the policy debate and who stays (or is forced) out (Schattschneider, 1975). Scope of conflict theory stresses that the definition of options is the supreme instrument of power. Policy options may differ in how likely they are to generate interest (pro and/or con) from the general public, industry groups, providers, and other stakeholders. As Chapter 1, section 3.4 (Framing) notes, the way an issue is framed can have considerable impact on the way people respond to that issue. One key issue is whether the focus is placed on individuals or on populations. Another is the balance between individual responsibility for one's own health (compatible with a stress on lifestyle) vs. recognition of the importance of environment and the social determinants of health. The way in which this question is framed can thus rapidly become ideological. For example, framing lifestyle as individual choice puts the emphasis on what people chose to eat, or how active they wish to be. In contrast, Milio has stressed that certain policy options make it easier or harder for people to make healthier choices (Milio, 1985). For example, design of cities can make it easier or more difficult for people to be physically active. Picking healthier foods may depend upon what is available, and their prices. Similarly, to the

extent that poverty is framed as a health issue, people may become more supportive of antipoverty strategies. One possible framing for social determinants of health is to emphasize the implications for children. Poverty is bad for children, and investments in ensuring that children grow up in a healthy environment can improve their prospects. Children cannot be seen to be responsible for their own conditions of birth, but there may indeed be debate about what is the responsibility of parents/families, and what is the responsibility of larger communities (Brown et al., 2010). Various efforts have been made to frame the policy goal of helping poor children develop into healthy and productive adults; these may include using the language of justice and equity, of economics (with the efforts framed as cost-effective investments), and/or of charity (with children easier to classify than adults as “deserving” poor). None of these arguments has proven particularly successful; opponents often frame antipoverty as providing incentives for people to be lazy and “unjustly” take resources away from those who work hard.

***4. Who would be responsible for implementing these policy alternatives? Discuss the roles of government, “civil society,” the market, and individuals and their families. What values/ideologies are reflected?***

A variety of social theories suggest different conceptualizations of appropriate governing roles for the state (see Chapter 1, section 3.2, Role of the State), and different possible roles for public vs. private actors.

Depending on the policy agenda and the objectives for change, the private sector may be better equipped to make changes more easily and with less expense. For example, intersectoral partnerships between the public and the private sectors may be more successful in addressing job training and related employment issues. In turn, the public sector can have various levers at its disposal for other policy problems. Aside from direct provision of services, government could: provide public education, change institutional structures that create silos in funding and responsibilities, broker industry/employer policy changes or provide various incentives to do so, provide direct funding; set standards or guidelines, and/or in other ways encourage cross-sectoral solutions.

Another factor that may impede effective healthy public policymaking is intra-governmental: different actors (even within the same level of government) may have different priorities. Note the list of ministries in the provincial government in Appendix C of the case. Who would need to implement the different policy options that might be selected? How high a priority would such actions be for that ministry? If, for example, one preferred policy option was to address unintentional injuries, how might that be done? Who would be responsible for improving road safety? Product safety? Workplace safety? If one wished to address respiratory system diseases, how might that be done? If one option would be improving air quality, who would be in charge? What if these measures were seen to harm job creation? Would lower incomes and unemployment have worse health impacts? Steinmo et al. (1992) documented the influence of both state and societal institutions on the ideas, interests and the distribution of power in a policy field. Milio reported on an international survey of public policies for health, and suggested that the following approaches were being used (Milio, 1987):

*Targeted Approach:* Consists of focussing on a specific area of public policy or on a particular disease or problem area, and building a coalition around it. This sort of approach has been used for tobacco control, and for Aboriginal health. One key feature is that the scope of conflict tends to be limited to those most interested in that area.

*Policy-Planning Structure Approach:* Consists of changing the institutional structures to set up new policy-making mechanisms that may facilitate the development of intersectoral policies. Typically, such mechanisms consist of intersectoral advisory committees; they may or may not be able to act on their proposals.

*Participatory Planning Process:* Consists of establishing a mechanism for public participation in policy development. The government consultation process, which gives stakeholders an opportunity to communicate with policy makers, is an example of a participatory planning process.

What are the likely similarities and differences between what would be recommended using these various approaches? For example, who would be likely to participate? Who would not? How might that affect priorities?

A related question relates to relationships inside government, and how organizational structure affects policy communities (see Chapter 1, section 4.2). There has been a tension between sectoral ministries (e.g., education, health), thematic ministries (e.g., ministries focused on children) and Cabinet Office (which is expected to focus on government as a whole). In different provinces, there have been efforts to set up *super ministries* with wide mandates; most have disappeared in subsequent governmental reorganizations. Where such functions as public health, occupational health and safety, and health promotion should be located is not always obvious. The absence of a strong constituency pushing for health (as opposed to health care) also makes these activities more vulnerable to budget cuts.

### **5. What policy instruments might you employ?**

Chapter 1, section 5.2 (Policy/Governing Instruments) discusses the various policy instruments that can be employed. Government can use informational/*exhortation* mechanisms. For example, the Participaction campaign urged people to exercise. Canada's Food Guide urges healthy eating. Government can also use *expenditure* to spend money on key programs. For example, government could subsidize recreational programs, improve road safety, build affordable housing, etc. *Taxation* can also be used (e.g., Canada's federal government has offered tax deductions to help parents offset some of the costs of enrolling one's children in recreational programs). *Regulation* is a key mechanism, and has been used extensively (e.g., regulate emissions to improve air quality; ban tobacco sales to minors). *Public Ownership* is also used (e.g., public parks). The class may wish to discuss which policy instruments might be used, and for which policy goals.

### **6. Discuss the campaign against smoking. What does it tell you about the strengths and weaknesses of health promotion campaigns?**

One of the most successful examples of health promotion has been the anti-smoking campaigns; it also illustrates the limitations. Initially, anti-smoking programs were seen as examples of the "nanny state" intruding on personal freedom. (Similar arguments are still used about discouraging junk foods; see Chapter 4, Trimming the Fat.) Even at that time, there was limited support for not allowing minors to buy cigarettes, but little support for other measures. However, once the argument was framed in terms of "second hand smoke" and the need to prevent smokers from harming other people against their will, prohibitions on smoking in most public places spread relatively quickly. Another policy instrument that can be used is taxation. If the policy goal is to decrease the likelihood that young people begin to smoke, increasing the price of tobacco is likely to be helpful; similar "sin taxes" may be used to discourage (and profit

from) alcohol or gambling. However, opposition grows if one can frame this in terms of an antipathy to taxes in general. In practice, high taxes in one jurisdiction have often encouraged smuggling from lower-taxed jurisdictions, which can be used to evoke fears of crime. The appropriate level of taxation on cigarettes can thus be framed in terms of needing to be low enough to discourage smuggling (anti crime), or needing to be high enough to discourage smoking (pro health), with the question of the impact on revenues being another variable (“sin taxes” produce less revenue if they successfully discourage the sins). Similarly, policies around healthy food can be framed as enhancing personal choice by helping inform individuals about the nutritional content of individual food items, or as trying to force individuals to change their behaviour “for their own good” and thereby improving the health of the population. One key difference between tobacco policy and food policy is that it is harder to make the “harm to others” argument with respect to eating (except indirectly via the implication for health costs), so policies to encourage healthy eating have had to rely more heavily on education than on regulations.

**See also in Chapter 1:**

- 1 What is Policy?
- 2.2.1 Federalism in Canada: *The Constitution Act, 1867*
- 3.2 Role of the State
- 3.3.3 Equity
- 3.4 Framing
- 4.2 Policy Communities
- 4.3 Scope of Conflict
- 5.2 Policy/Governing Instruments
- 6.3 What is Health?
- 6.3.1 Public Health
- 7.2 *Canada Health Act*
- 9.1 Canadian Data
- 9.2 Comparative Health Data

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## **Chapter 4: Teaching Notes**

### **Trimming the Fat: Dealing with Obesity**

*Katerina Gapanenko, Catherine L. Mah, Shaheena Mukhi, David Rudoler, and Raisa B. Deber*

#### **Outcome**

Obesity rates have continued to rise, but at the time of writing, relatively few policies had been implemented to address that issue. One reason is some ambiguity as to where to start; obesity is a very complex issue that involves almost all aspects of modern life (food industry, agriculture, healthcare, transportation, etc.). Another reason could be that there are often not clear boundaries between normal and excess eating, or between healthy and unhealthy food.

#### **Possible Points for Discussion:**

##### ***1. What causes obesity? Why is it worth addressing?***

Obesity is a complex condition involving social, economic and psychological dimensions, and its resolution is likely to require involvement of multiple levels of government as well as, non-governmental organizations, industries, agriculture, education, social services and individual citizens (Sacks et al., 2008). As noted in the case, obesity can be seen as resulting from genetic factors, individual lifestyle behavior, and/or the environment within which people live (see also Chapter 1, section 6.3, What is Health?). Similarly, obesity may be seen as an individual health burden, a population health burden, and/or a health care system/cost issue. Obesity can be seen as both a risk factor for other, noncommunicable diseases (including those linked with mental health and wellbeing), and/or as a risk factor in and of itself. Obesity is often associated with social and cultural stigma; that can in turn affect individual self-esteem, and affect the risk of bullying. From the viewpoint of population health, one may focus on current and/or on future risks (which may justify an emphasis on childhood obesity). To the extent that there is a link between obesity and other social determinants of health, there may be a particular impact on vulnerable populations. Obesity is seen as a health risk internationally, in high-income, middle-income, and low-income nations (Sassi, 2010), although different causes and potential solutions may come into play in different settings.

The causes of obesity can thus be viewed through multiple lenses. If one focuses on individual behaviour, one would try to encourage healthier eating, as well as physical activity and exercise. Access to fresh fruits and vegetables however, depend on complex global food supply chains. Another key factor is the built environment, which may affect how easy it is to be physically active on a daily basis, get to a grocery store, etc. Many communities have been designed to make it difficult to get around without a car. This may also depend on the climate, weather, on how mobile individuals are, on how frequently they shop for groceries, and so on. There are also complex dynamics involving the availability of food, its price, and how affordable it is; this in turn relates to household income and household spending, and economic conditions.

Note that even defining when someone is obese, or indeed when someone is overweight, is not always simple. There is a tendency to rely on Body Mass Index (BMI), although this may not always be an optimal measure.

**2. What policy options might you recommend? What are their advantages and disadvantages? What views do they reflect concerning the appropriate role of the state in addressing obesity? Discuss trade-offs between the importance of protecting the health of the population, respecting individual liberties, and controlling health expenditures.**

In general, an emphasis on liberty (see Chapter 1, section 3.3.2) would encourage a hands-off approach, although information-based approaches (e.g., public education campaigns) could be defended as helping to create a more informed consumer. Liberty-based arguments might include the freedom of people to buy what they want, and to eat what they think tastes good. Cultural sensitivities could also be invoked if restrictions were proposed for “unhealthy” foods associated with particular ethnocultural or religious groups. A job creation focus might speak of the importance of allowing business to sell what they want, with some talk about the importance of the resulting jobs that might be created; a local business focus might highlight the needs of local food producers and sellers.

In terms of effect of obesity on the economy, there are several offsetting possibilities. Higher rates of chronic disease could lead to higher needs for care, and higher costs. However, if this results in lower life expectancy, it could lower lifetime health system costs (since dead people do not use health care), as well as lower costs for other programs (e.g., pensions).

As noted in Chapter 1, section 5.2 (Policy/Governing Instruments), policy makers, both public and private, can use a range of *policy instruments* (Howlett et al., 2009). Hood’s NATO taxonomy (Hood, 1983) speaks of Nodality (i.e., information-based instruments), Authority (i.e., laws and regulations), Treasure (i.e., taxing and spending), and Organization (i.e., changing governing structures). The least coercive/intrusive approaches involve providing *information* and/or encouraging individuals and organizations to behave in certain ways. Examples could include public information campaigns, exhortation, performance measurement, and the establishment of commission and inquiries. These tools are relatively inexpensive and do not violate individual liberty. However, health promotion messages (including anti-smoking campaigns) have tended to be more effective with more affluent and educated individuals. Although the overall health of the population may improve, equity (see Chapter 1, section 3.3.3) may become worse. Another possible consequence is that it may be easier to “blame the victim” for not listening to these messages, and refuse further help.

Food guides are one example of an inexpensive information-based policy instrument. The Canadian government uses a food pyramid, other countries (e.g., Portugal, Sweden and the United Kingdom) use a plate divided into segments (food groups) to explicitly drive understanding around portion sizes. Health Canada created a web-based tool, *My Food Guide Servings Tracker* that provides food calorie information to people (Health Canada, 2012). The public health unit in the city of Hamilton, Ontario has worked with community partners to set up a Hamilton Partners for Healthy Weights to provide parents of children aged four to twelve with information.

Information can also include material about physical activity. For example, Health Canada with the Public Health Agency of Canada (PHAC) designed *The Eat Well and Be Active Educational Toolkit* to help health and education specialists teach children and adults about healthy eating and physical activity, and to encourage the public to take actions in order to maintain and to improve their health. A number of local governments provide information about the Canadian Children’s Fitness Tax Credit, which allows parents to claim a portion of the costs they pay to register children less than 16 in an eligible program of physical activity as a non-refundable tax credit.

Internationally, the government of England has launched a healthy living campaign *Change4Life* that informs families through TV cartoons that excess body fat leads to cancer, type II diabetes and heart disease. In 2010, the OECD issued a report about obesity rates and government practices in the OECD countries (Sassi, 2010). Schools in Berkeley, California, have set up vegetable gardens to teach students about food and nutrition, and even to supply food to the school cafeterias (which involves using both Information and Treasure based policy instruments). A rigorous nutrition education program in Singapore schools, *The Trim and Fit Scheme*, reduced obesity rates among that country's schoolchildren by 33% to 50% depending on the age group. US First Lady Michelle Obama has championed healthy eating and school gardens.

What are sometimes termed authority-based instruments use rules (e.g., laws, (regulations, directives) to compel certain kinds of behaviour, prohibit others, set standards, and to outline and enforce penalties for those who do not comply with these rules (see also Chapter 1, section 5.2.1, Regulation). These may be promulgated by governments and/or by other organizations (e.g., arm's length regulatory bodies). For obesity, one would probably focus on regulating the food industry (which is sometimes referred to as "Big Food"), as opposed to trying to regulate individual consumers. Regulations are typically relatively easy to implement, particularly if little information is required to achieve implementation, and are typically not directly costly to government (although they may involve public costs if the regulations require enforcement). However, such regulations may be costly to those being regulated. They will affect the free-market practices of the food industry, and regulations applied directly to individual behaviours will infringe upon individual liberties (e.g., proposed prohibitions in New York City against selling large sized glasses of sugared beverages evoked considerable controversy). In addition, they are harder to tailor to respond to individual variation. An ongoing debate results as to how much uniformity is required, and hence whether regulations should be implemented at the local, sub-national (e.g., provincial/territorial), national, and/or international levels.

One example of regulation in the food area is food safety; depending on where products are being sold, various levels of government are expected to regulate food producers to ensure that toxic or harmful substances do not contaminate food products. Another is nutritional labeling of food products. In Canada, the federal government may regulate food companies. This approach can be framed as a way to correct information asymmetry by providing nutrition facts and ingredients on packages to buyers in a way that is relatively non-coercive to food consumers. However, the cost of food labeling cost falls on the shoulders of food companies (i.e., private industry), and does place some costs on government to maintain and enforce standards. Small producers and family-type restaurants may find it particularly difficult to pay for the cost of testing and printing the labels and could even be put out of business. In addition, providing this information to consumers does not guarantee effective information uptake and interpretation, although it can be extremely helpful. (It is also useful to those with dietary restrictions, either due to allergies, or due to religious reasons.) To make labeling work, the public also needs to be educated on how to read labels to make healthy choices.

More coercive forms of regulation might specify what can or cannot be present in processed foods (e.g., reducing sodium, eliminating trans fats). In 2003, Denmark regulated (and effectively banned) the sale of foods containing trans fats; some other jurisdictions (including Switzerland) did the same. Canada's approach has been labeling and encouraging manufacturers

to “voluntarily” reduce trans fats. In 2008, Calgary became the first city in Canada to ban trans fats from restaurants and fast food chains.

What Hood calls treasure-based instruments include financial transfer to individuals and organizations from governments or under government’s direction and can take a form of incentives or disincentives that encourage or discourage a particular activity (e.g., taxation, tax credits and subsidies, grants and user charges). For example, in 2009, the Ontario government invested \$75 million and increased the number of bariatric surgeries it would pay for to 1,470 annually. This was still below the demand (it was estimated that more than 3,000 a year sought that treatment). In terms of disincentives, soft drinks, sweets and snack foods are subject to sales tax in Canada, while most other foods purchased in grocery stores are not. A review of European activities found several examples of this approach (Lorek, 2011). They have not always been successful. For example, Romania passed a fast-food tax in January 2010, but withdrew it later. In 2011, Denmark brought in a “fat tax” on such foods as chocolate, sugared soft drinks, saturated fats in oils, dairy products and meat. It was very unpopular, and repealed a year later. Hungary also introduced a “junk food tax” and France a tax on all sweetened drinks. A study concluded that these taxes would have to raise prices by about 20% to have an impact (Mytton et al., 2012).

These policies can work in many ways. For example, US subsidies for corn and soy changed the entire food system in that country by encouraging the use of high fructose corn syrup and hydrogenated vegetable oils (trans fats). In turn, this reduced the cost to manufacturers of making high-sugar and high-fat products. *Taxation* and pricing has been an effective government policy used against tobacco because of the price-demand elasticity, meaning that people not yet “addicted” to tobacco became less likely to purchase these products. However, unlike cigarettes or alcohol, people need to eat food in order to live. Neither can one easily restrict consumption of foods to those over a certain age.

Raising taxes on unhealthy goods (e.g., sugar-sweetened beverages, fast food) and earmarking the associated revenues for health-related activities has been recommended by some, but this policy is also perceived to be controversial and there are many economic and political barriers for widespread adoption (see Appendix A of the case). Any policy that raises taxes without complementary interventions (e.g., subsidies for healthy food) may be viewed as inequitable. Defining which foods should attract such taxes (and how high the taxes should be) is also a policy challenge. Evidence suggests that small to moderate taxes on unhealthy food show minimal to no impact on consumption (Madore, 2007). However, large taxation can lead to illegal production or smuggling. For example, illegal candy sales cost Denmark millions of kroner, because the industry could not compete with smuggled candies from Sweden.

Tax incentives to promote physical activity have also been used in a number of countries. Since 2005, Nova Scotia has provided a Healthy Living Tax Credit to help children and youth to stay active. In 2006, the Government of Canada introduced the Children’s Fitness Tax Credit. These tax credits are, in general, less valuable to those individuals too poor to have much taxable income.

Organizational-based instruments may involve reorganization of the structure of government and/or its internal functioning. Examples of this instrument include the creation of public enterprises, market creation and government reorganization. One example was the creation of an Ontario Ministry for Health Promotion and Sport in 2005, which was given responsibility for health promotion and healthy living programs. However, in 2011, this ministry

was merged back into the Ministry of Health and Long-Term Care (MOHLTC). Varying levels of government can also set up bike lanes, open recreation centres, provide school lunches, etc.

***3. Discuss the impact of how obesity policy might be framed on what policies might be selected.***

Policy options may vary, depending on how the causes of obesity, and the burden it represents, are perceived. How obesity is addressed (or if it is addressed at all) may be related to how the issue is framed (see Chapter 1, section 3.4). The issue could be framed as one that affects the entire population, or only the morbidly obese, or as an issue of childhood obesity. It could be seen as a production side issue (related to food availability, supply chains, and the preferences of Big Food), or as one of consumption. It could be framed as an issue of individual responsibility, or framed in terms of the need to address the social determinants of health.

An interesting comparison can be made between anti-obesity and anti-tobacco efforts. Initially, tobacco was framed in terms of the potential to cause harm to the smoker, and evoked opposition from those believing that the “nanny state” had no business telling people what to do. More success was achieved when it was framed as the potential harm to non-smokers through second-hand smoke. Another framing was in terms of the potential cost to society of treating smoking-related illness; this evoked opposition on the grounds that it amounted to “blaming the victim” and might undermine the premises of universal health care. Obesity is harder to frame as a risk to others, except in the sense of incurring health costs that others might have to pay for. This could become problematic, particularly if the argument was extended to imply that people should not be cared for at public expense if their condition was seen as “their fault”.

Another complication is that policies may have unintended consequences. One example has been efforts by environmentalists in several places (including the University of Toronto) to discourage use of plastic water bottles; this has been framed as discouraging the use of environmentally unfriendly products. However, this policy has also had the perverse effect of banning water from most vending machines, while permitting the sale of highly sugared sodas. Yet another way to frame the question of vending machines can be in terms of economics (profits generated for the venue). The preferred options are likely to vary, depending on how the question is framed, and who is making the decisions.

***4. What criteria are you using in deciding what policy options to recommend? How might your recommendations differ if you were: the deputy minister of agriculture? Of finance? Of economic development? Advising the restaurant association? The food industry? The diabetes association?***

Criteria might include effectiveness, feasibility, public support, cost, and how they would be enforced. One issue is that policy interventions in one area could have impacts (or unintended consequences) in other areas. Another important question without a clear answer is who should be involved in decision making on policy to address obesity? What sectors? How about the private sector or food industry role? Food production and distribution encompasses a very diverse array of actors. Another is the time frame; prevention may have long-term payoffs, but electoral cycles make it difficult for policy makers to sustain such policies if there is little to show for it in the short term.

Another difficulty is that many organizations are involved, including all levels of government, as well as private stakeholders. To what extent are ministries inclined to cooperate and pursue activities that may not be seen as part of their core mandate? Another dilemma is

when policy goals conflict, particularly when different stakeholders place different weight on different goals (see also Chapter 1, section 3.3, Policy Goals). For example, the agriculture policy community is interested in producing good tasting (and good selling) food, but its main goal is promoting the economic well being of farmers. In the US, high fructose corn syrup is now in many foods, in part due to agricultural price supports for growing corn. Similarly, food companies have a strong interest in making a profit and staying competitive. For example, 2011 newspaper reports quoted the incoming CEO of Campbell's Soup as saying that she would reverse the company's reduction of salt in their canned soups, on the grounds that it had caused sales to slow, and had caused the price of the company's shares to drop.

Restaurant associations represent interests of restaurants, and may not support policies encouraging them to display how many calories are in each menu item, particularly since the restaurants would have to pay to have laboratories calculate this. In addition, in many restaurants, food is prepared with creativity and variation, which would pose difficulties in accurate calorie calculation.

The class may wish to consider the roles and responsibilities of those ministries with responsibility for such activities as health promotion, sports, education, finance, children and youth services, community and social services, agriculture, and transportation, and how policies might vary, depending on which organizations are trying to deal with the issue (see also Chapter 1, sections 4.3, Scope of Conflict, and 5.4, Policy Implementation). Another example of a potential clash between policy goals can occur at the municipal level. For example, the City of Toronto attempted to cut its budget by, among other proposals, increasing fees for using community recreation facilities (pools, skating rinks, etc.) This had negative implications for physical activity, particularly in poorer neighbourhoods, and was partially reversed. Another question is whether playgrounds are available and accessible; in some US cities, they were locked up, ostensibly on grounds of public safety. Considerable attention is being paid to the food available in school cafeterias; in some jurisdictions, efforts to ensure that only healthy food was served led to many students going to local fast food restaurants instead, and to proposals to close school cafeterias which were now less profitable. In the private sector, one might ask what homes for the aged serve their residents, or hospitals serve their patients, particularly given pressures to reduce costs per patient. One might also ask what products the retail food operations for visitors (and outpatients) in those same institutions sell.

The state can play a role of a facilitator to coordinate, subsidize and encourage people to be more physically active. However, such efforts may have more effect on those who are already richer and healthier.

### **See also in Chapter 1:**

- 3.2 Role of the State
- 3.3 Policy Goals
  - 3.3.2 Liberty
  - 3.3.3 Equity
- 3.4 Framing
- 4.3 Scope of Conflict
- 5.2 Policy/Governing Instruments
  - 5.2.1 Regulation
- 5.4 Policy Implementation
- 6.3 What is Health?

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**The following websites may also be helpful:**

Change4Life. <http://www.nhs.uk/change4life/Pages/change-for-life.aspx>

Employment and Social Development Canada. *Health - obesity*.  
<http://www4.hrsdc.gc.ca/.3ndic.1t.4r@-eng.jsp?iid=6>

Government of Canada. *Childhood Obesity* <http://www.healthycanadians.gc.ca/kids-enfants/obesity-obesite/risks-risques-eng.php>

Hamilton Partners for Healthy Weights <http://www.dailythingscount.ca/aboutUs.html>

Health Canada.

*Canada's Food Guide*: Government of Canada. <http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/context/evid-fond-eng.php>

*My food guide servings tracker* <http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/track-suivi/index-eng.php>

Public Health Agency of Canada, The Eat Well and Be Active Educational Toolkit  
<http://www.hc-sc.gc.ca/fn-an/food-guide-aliment/educ-comm/toolkit-trousse/index-eng.php>



## **Chapter 5: Teaching Notes**

### **Trouble on Tap: Water in Walkerton**

*Brenda Gamble, Nancy Kraetschmer, Kenneth Cheak Kwan Lam,  
Catherine L. Mah, Caroline Rafferty, and Raisa B. Deber*

#### **Outcome**

As noted in the case, the contaminated water in Walkerton had resulted in the deaths of seven individuals and at least 2300 cases of illness from infection with *E. coli* O157:H7 and *Campylobacter jejuni*. The public judicial inquiry under Justice Dennis O'Connor released its final report in 2002 (O'Connor, 2002a, 2002b). It concluded that among the individual and structural factors contributing to the events in Walkerton were: a long history of unacceptable practices by Public Utilities Commission (PUC) operators, including the concealing of information by Stan Koebel, its general manager; operational deficiencies related to water monitoring and treatment; and public sector budget reductions in 1996 that had led to the downloading of laboratory services for water testing.

The Inquiry report confirmed that the source of the contamination was the manure spread on the farm near Well 5, but absolved the farm owner of responsibility, since he had “followed proper practices”. It praised the Grey Bruce Health Unit, and noted that the PUC had concealed results from them. Had these been disclosed, the report felt that 300-400 illnesses would have been avoided. However, they added that “In responding to the outbreak, the health unit acted diligently and should not be faulted for failing to issue the boil water advisory before Sunday, May 21,” although they felt that the advisory, once issued, should have been more broadly disseminated.

Other actors were seen less favorably. The report suggested that “The outbreak would have been prevented by the use of continuous chlorine residual and turbidity monitors at Well 5”, and argued that the failure to do so “resulted from shortcomings in the approvals and inspections programs of the Ministry of the Environment (MOE)”. The MOE’s inspections program was faulted for its failure to detect the Walkerton PUC’s improper practices. The Walkerton Public Utilities Commission (PUC) operators were blamed, both for lacking “the training and expertise necessary to identify either the vulnerability of Well 5 to surface contamination or the resulting need for continuous chlorine residual and turbidity monitors”, and for not properly measuring the chlorine residuals there on a daily basis. The report added that “For years, the PUC operators engaged in a host of improper operating practices, including failing to use adequate doses of chlorine, failing to monitor chlorine residuals daily, making false entries about residuals in daily operating records, and misstating the locations at which microbiological samples were taken. The operators knew that these practices were unacceptable and contrary to MOE guidelines and directives.” The report also blamed the PUC commissioners in 1998 for failing to properly respond to the MOE inspection report setting out concerns about operating deficiencies and water quality, but absolved the existing PUC commissioners.

The report also placed some blame with the province, arguing that “The provincial government’s budget reductions led to the discontinuation of government laboratory testing services for municipalities in 1996. In implementing this decision, the government should have enacted a regulation mandating that testing laboratories immediately and directly notify both the MOE and the Medical Officer of Health of adverse results. Had the government done this, the

boil water advisory would have been issued by May 19 at the latest, thereby preventing hundreds of illnesses. The provincial government's budget reductions made it less likely that the MOE would have identified both the need for continuous monitors at Well 5 and the improper operating practices of the Walkerton PUC."

Justice O'Connor went on to make 121 recommendations intended to improve the protection, operation, management, treatment, and distribution of drinking water for the province, including advice on the setting of drinking water standards, greater accountability and transparency at all levels of government, and regulatory reforms. O'Connor advised that the provincial government should play a strong role in regulatory oversight and standard-setting, while the municipalities should be responsible for the revenue to finance local water systems.

### **Subsequent Events**

Subsequently, more than \$11 million was spent in reconstructing Walkerton's water system and installing temporary filtration. In addition to the judicial inquiry, a series of other independent, formal investigative processes were held, including an investigation by the Ontario Provincial Police, a Coroner's Inquest into some of the deaths that were believed to be linked to the *E. coli* outbreak, and a Ministry of the Environment investigation into the events that led to the contamination of the municipal water system. The class-action lawsuit filed by customers of the Walkerton PUC and other individuals who had consumed contaminated PUC water was settled quickly in March 2001; the Walkerton Compensation Plan made no fault compensation available to all eligible applicants. By September 2007, all claims had been settled, and the Walkerton Compensation Plan closed its administrative office. A report issued in 2011 argued that the plan had been successful, although the local newspapers suggested that not all claimants were happy.

As a direct result of the Walkerton tragedy, immediate changes were made to the regulations under the *Ontario Water Resources Act* that managed Ontario's standards for drinking water. Ontario Regulation 459/00, the Drinking Water Protection Regulation (later renamed the Large Water Works Regulation) was gazetted in August 2000. These changes put into law the requirements for large waterworks, regardless of who owned them, to: 1) meet minimum treatment requirements, 2) have their drinking water tested by an accredited laboratory, 3) immediately notify the proper authorities of adverse test results (both the Ministry, and the local Medical Officer of Health), and 4) post notice signs to alert the public where water is untested or unsafe. Among the regulations under the act were provision for quarterly reporting, requirements that laboratories and waterworks owners provide written confirmation about how Adverse Water Quality Incidents were being dealt with, and the hiring of dedicated drinking water inspectors.

In order to implement the recommendations of the Walkerton Inquiry, Ontario developed an entirely new legislative framework that provided the foundation for a provincial source-to-tap drinking water safety net. Regulations under the *Safe Drinking Water Act, 2002* and the *Clean Water Act, 2006* updated the original requirements of Ontario Regulation 459/00 and began addressing broader issues such as source protection, quality management standards and licensing, municipal standards of care, and the risks of lead exposure. The Ministry of the Environment was reorganized to have a dedicated Drinking Water Management Division, a Chief Drinking Water Inspector, and over 100 drinking water inspectors delivering the provincial inspection program. The approach has shifted from a "command and control" approach with the regulated community to a collaborative approach including all stakeholder groups. Compliance

ratings and drinking water quality results have improved steadily in the decade since the Walkerton outbreak, and most observers agree that a significant transformation for drinking water quality assurance has occurred in Ontario.

The Walkerton outbreak also led to an environmental group of lawyers and scientists, (Ecojustice) to compile report cards on how various jurisdictions were progressing in ensuring water protection. Their third report was issued in 2011; it gave Ontario (but only Ontario) an A grade; the federal government received an F (Christensen, 2011).

The careers of the Koebel brothers were destroyed. Although initially the town approved a buyout package for Stan (\$84,000, reduced from the initial offer of \$98,000), the brothers were eventually brought to trial on charges of forgery, breach of trust, and common nuisance. In 2004, a plea bargain resulted in them pleading guilty to the common nuisance charges. Stan was sentenced to one year in jail and Frank to 9 months under house arrest. Stan was released after serving 4 months, and moved to a new community. As of the timing of writing, Frank still lived in Walkerton.

### **Possible Points for Discussion:**

#### ***1. Why did the tragedy occur? Discuss how “framing” might affect problem identification.***

As discussed in Chapter 1, section 3.4 (Framing), framing theory suggests that the way in which a policy issue is framed or defined can influence policy decision-making and outcomes. Different stakeholders may, and often do, frame a problem differently and this can lead to tensions in the policymaking process. Different frames mean that stakeholders can talk past each other, by making entirely different arguments about the same policy problem. Framing in terms of problem definition can be particularly complex, since different definitions of what caused a particular policy problem can incorporate vastly different ideas about what the correct solution might be.

For example, one approach would be to frame the Walkerton events as the fault of errors made by individuals (e.g., Stan and Frank Koebel). In that case, all that was necessary was to hire better people, and perhaps punish those individuals who made the mistakes. One leading expert on quality improvement in clinical care contrasted the “bad apple” theory with “continuous quality improvement” (CQI) approaches. CQI stresses the importance of how care is organized, and argues that well designed structures can help in encouraging high performance and ensuring that errors can be caught before catastrophic consequences result (Berwick, 1989). If so, a better designed system might have incorporated provisions to ensure that any mistakes (particularly those with potentially severe consequences) would be more likely to be caught. Indeed, the previous system had detected problems with the well, although it had not acted on these findings and required the local PUC to correct the deficiencies.

The class might wish to discuss the implications of alternative ways of framing the Walkerton tragedy. Some other possibilities could include: the potential impact of budgetary reductions, the implications of using public or private operators (including privatizing water testing), and the appropriate design of regulatory oversight.

Frames can tell us what goals stakeholders hold to be important and how stakeholders have made sense of a particular policy issue, in a way that expresses conscious as well as tacitly held beliefs. Thus framing is also about symbolism and the creation of policy stories, which are important parts of political and policy discourse and debate. The Harris government was skilled at framing, including the titles given to legislation. For example, the bill that prohibited legal

action against the provincial government for failure to enforce environmental regulations was titled *The Environmental Approvals Improvement Act, 1996*; similarly, the bill that eliminated the drinking water surveillance program and closed four provincial labs was titled *The Water and Sewage Services Improvement Act, 1997*. Clearly, whether these policy initiatives constituted improvements could be open to question.

Framing is also linked to *scope of conflict* (see Chapter 1, section 4.3, Scope of Conflict) (Kellow, 1988; Schattschneider, 1975). Depending upon how the problem is defined, there are implications for how (and where) it will be dealt with, and for which stakeholders have a right to sit at the policy table. In this case, the provincial government preferred to frame the issue as an isolated problem related to the competence of local workers. This framing deflected public criticism from regulatory deficiencies, factory farming practices, and privatization concerns. It allowed them to deal with it through a narrow, albeit locally helpful response of eliminating the negligent workers, rebuilding the Walkerton water system and providing no fault compensation to the citizens of Walkerton, without having to consider broader questions about the role of government, regulatory approaches, etc. (However, as noted above, the province also did take action under the Drinking Water Protection Regulations.)

## ***2. Discuss the concept of public goods and externalities as they apply to the case. Is water a public good?***

As noted in Chapter 1, section 3.5 (Public Goods and Externalities), public goods are defined as being nonrivalrous and nonexcludable. Using this definition, drinkable water would not meet either of these criteria, and hence would not be classified as a public good (although clean air would be). Water would not be classified as nonrival, because water consumed by one person cannot be consumed by another. (Note that although this point is somewhat trivial in much of Canada, where there is ample water in most places, access to water is becoming a pressing problem in many other jurisdictions, where water shortages are emerging.) Neither is water nonexcludable; it is simple to cut off supplies to those not willing to pay. Whether treating water in this way is either wise or humane is another issue, relating to views about what individuals should be entitled to, regardless of their ability to pay. (One exception is if polluted water causes infectious diseases that could then spread to those not consuming the water; in that case, public goods theory would clearly apply.)

Similarly, health care services to individuals would also not qualify as a public good. However, in most nations, there is a sense that people should receive certain care if it is “needed”. The category of “merit goods” or “club goods” is sometimes used to apply to goods and services such as health care where their use is limited to those who satisfy certain conditions of membership (e.g., citizenship). In that sense, access to a “reasonable” amount of clean water would probably qualify as a merit good. One approach sometimes used while remaining within a quasi-market is cross-subsidies, where customers overpay for some things, but are undercharged for others. One example was regulatory policy for telecommunications; for many years, policy makers believed that the ability to make local telephone calls was sufficiently important to warrant ensuring that poorer people still had access; local telephone monopolies were thus allowed to overcharge for long-distance calls, but undercharge for local service. This approach collapsed once competition entered the telephone market. Similarly, the post office often cross-subsidizes mail delivery; it costs the same to send a letter within a densely populated city as it does to send a letter across the country to a remote community. These cross-subsidies may be hidden or explicit.

Although water does not qualify as a public good, it does present significant issues relating to externalities. When someone contaminates a water supply, they impose costs on others. Similar issues arise with respect to air quality, and even land use planning. A common way of dealing with externalities is regulation.

***3. What policy options would you suggest? Discuss the use of various policy instruments in implementing these options. What is the rationale for regulation? In general? For water quality? For air quality? Land use planning?***

Regulation is a type of policy instrument (see Chapter 1, sections 5.2, Policy/Governing Instruments, and 5.2.1, Regulation). It involves high coercion (in that those being regulated must comply with the rules), but is also characterized by shifting the costs of compliance from government to those being regulated. Those wishing to reduce the role of government frequently decrease the use of regulation, often on the grounds that regulations represent “red tape” and “interference with private concerns”, as well as decreasing competition and/or increasing costs. Rationales for regulation often relate to the characteristics of the goods and services and who provides them, and often involve attempts to balance the degree of risk to the public against the costs of enforcing the rules. For example, if there are natural monopolies, then regulation may be necessary to prevent providers from exploiting their customers. Key examples include cases where infrastructure is expensive and unlikely to be duplicated by competitors (e.g., telecommunications wiring, sewage and water services, public transit). In that case, regulators may control the price that can be charged. Regulation may set up rules about who can access services (e.g., many European health insurance systems regulate benefit packages, and do not allow the insurers to refuse to cover high risk individuals). Another rationale is the potential for harm from poor performance (e.g., food and water safety). Water safety would appear to meet many of these criteria.

Other policy instruments might also be employed (Doern & Phidd, 1992). *Exhortation* could be used to provide public information about water quality (allowing people to select how pure they wished their water to be), or to attempt to convince polluters not to dump waste into the water supply. *Expenditure* could be used to help subsidize the costs of providing clean water, and of testing it. *Public ownership* could be used to run various water services; note that this was the model for testing until policy decisions were made to close provincial laboratories and encourage private testing.

***4. Discuss the advantages and disadvantages of: direct public provision; public-private partnerships; private delivery for supplying and testing water. How do these relate to the production characteristics of the services being provided?***

The terms “public” and “private” have multiple levels, and can be used to refer to how goods and services are financed, as well as to how they are delivered (see Chapter 1, sections 6.1.1, Public and Private and 6.1.2, Financing and Delivery) (Deber, 2004). For example, “private” may refer to private for-profit corporations, to private for-profit small business, to not-for-profit organizations, or to individuals and their families. Most health care provided by Canadian physicians is publicly funded (via general revenues) but privately delivered by physicians who can be seen as for-profit small businesses. “Privatization” is a term that is often used when a good or service that was previously public becomes private. Once again, this can apply to the mode of financing or delivery. In the case, the delivery of water testing services was privatized through contracting out to private for-profit firms.

The dominant model for providing water service in Ontario, as in many jurisdictions, is public, with water systems owned and operated by local governments through their public works departments and Public Utilities Commissions (PUCs). However, the private sector is extensively involved in many aspects of water service delivery. Municipalities have typically used the private sector to provide some or all of the following: consulting engineering services (e.g., process selection, infrastructure design, systems planning, operational audits); construction services (e.g., pipeline, treatment plant, and/or building construction); material supply (e.g., equipment, construction materials, treatment chemicals); repair services (e.g., electrical, mechanical); testing and laboratory services (e.g., materials, effluent); and field services (e.g., pipe inspection and cleaning, hydrant maintenance, flow monitoring). There is considerable debate among water experts about how best to set up a water utility. One issue is whether the water utility should be stand-alone (usually referred to as a PUC) or should be part of a municipal department having responsibility for a number of services, including water. There are also issues about how large these units should be (e.g., should smaller communities work together?). Issues raised may include: the size needed to possess the critical mass to support necessary expertise, including professional engineering input; the extent to which water is (and should be) sheltered from budget constraints affecting municipal governments; the extent to which PUCs share information among themselves; and the implication of differing policies regarding borrowing for capital projects. In Canada, blessed with extensive water resources, water utility rates have been very low by international standards; in Ontario, the average household paid approximately \$200 annually for water. To the extent that keeping these rates low means scrimping on investment and operating expenditures, the long-term probability of water quality problems may increase.

As noted in Appendix D of the case, one approach is to use Public Private Partnerships (P3s). A wide variety of arrangements can be used, which vary in the allocation of responsibility (and financial risk) between the public and private sectors.

Another issue affecting some Ontario PUCs has resulted because public accountability means that municipal councils control borrowing for PUC capital expenditures. Often, PUCs have been advised to create reserves from water revenues, and institute “pay as you go” policies for capital projects; these reserves may present an attractive source of revenues for other municipal priorities.

One key issue when services are contracted out is the ability to clearly define what constitutes good performance. Depending on the *production characteristics* of the service (see Chapter 1, section 5.7), this may be simple or very difficult. In the Walkerton case, the contracts for water testing specified how the test should be performed, but neglected specifying that the tests should be conducted by someone who understood what they meant, or that results should be conveyed to sources other than the client (here, the PUC) who had ordered them. One distinction between the former public model (where water was tested within the MOE) and the privatized model was that the for-profit company had an obligation to maximize their profits; it was not realistic to assume that they would go beyond the terms of the contract.

***5. What is the role of a municipal government? Discuss the implications of the relationships between municipal and other levels of government.***

In Canada, local government falls under provincial jurisdiction (see Chapter 1, section 2.2.3, The Roles of Local Government in Canada). This can present policy problems, particularly

when there is an imbalance between available resources and responsibilities. Note that the province can set policies and priorities for local governments.

As demonstrated by the Walkerton Commission, issues of jurisdiction complicated the ability to ensure that water was safe. Responsibility lay both with municipalities (as service providers) and the province (as regulator, a source of capital funds, and in the case of OCWA, as operator as well). Within municipalities, responsibility lay with both the elected officials (mayor, council), and the PUC board members (elected or appointed). Under the *Health Protection and Promotion Act*, the local Medical Officer of Health has the ultimate authority in judging whether water is safe for human consumption, but was not always in the loop for obtaining information about the results of water testing. In addition, at the time of the case, the *Ontario Water Resources Act* specifically exempted pollution due to farm waste; this was, in theory, dealt with through other mechanisms, including the Farm Pollution Advisory Committee, a joint committee of the Ministry of the Environment and the Ministry of Agriculture, Food and Rural Affairs, established under the authority of the *Environmental Protection Act*, which was given the ability to attempt to resolve such problems when voluntary cooperation by the farmer involved was not forthcoming.

#### **6. Discuss accountability. How might one ensure it?**

Accountability is a term that has become increasingly popular (see Chapter 1, section 5.6, Accountability). In particular, increased private sector involvement in matters such as regulation, standards-setting, and service delivery while public revenues are used as sources of funds has presented challenges for the legitimacy of governments and their ability to ensure transparent, clear linkages between the input of public funds and related outputs. Some also distinguish between responsibility and accountability. Particularly when tasks are delegated, the person who is responsible for completing a task may not be held accountable; that accountability may remain with those who had delegated the task. Accountability is often linked to oversight and leadership. In the Walkerton case, Justice O'Connor recommended in his final report for the Walkerton Inquiry that persons responsible for oversight of water safety and supply should be held to a legal standard of practice, much like the director of a corporation.

#### **7. Discuss street-level bureaucracy as it applies to this case.**

The term street-level bureaucracy refers to people who work on the front lines ("street-level"), where supervision is difficult or impossible (Lipsky, 1980). As noted in Chapter 1, section 5.3 (Street-Level Bureaucracy), there can often be considerable discretion in how particular tasks are performed, and street level bureaucrats have a substantial amount of autonomy in carrying out their day-to-day functions. Problems may arise when their actions do not always match the expressed policies or objectives of the organization or program as a whole. Examples of street level bureaucrats would include police officers or social workers, but also home care workers, or employees of the water treatment plant. The model for ensuring water safety relied heavily on the judgment of those operating the system. As described in the case, the Walkerton PUC was in the habit of falsifying test results; they also ignored problems (e.g., the breakdown of the town's chlorinating equipment, the MOE inspection reports). There were few mechanisms in place to ensure that corrective action would be taken. One option when it is not possible to monitor closely is to rely on professionalism (see Chapter 1, section 6.4, Professionalism). As professionals, street-level bureaucrats would both understand what they should do (and why) and be internally motivated to ensure that they follow professional

standards. This clearly did not apply to the Koebel brothers, who were not qualified as water operators, and demonstrated that they did not understand the possible consequences of their actions.

**See also in Chapter 1:**

- 2.2.3 The Roles of Local Government in Canada
- 3.4 Framing
- 3.5 Public Goods and Externalities
- 4.3 Scope of Conflict
- 5.2 Policy/Governing Instruments
  - 5.2.1 Regulation
- 5.3 Street-level Bureaucracy
- 5.6 Accountability
- 5.7 Production Characteristics
  - 6.1.1 Public and Private
  - 6.1.2 Financing and Delivery
- 6.3.1 Public Health
- 6.4 Professionalism

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**The following website may also be helpful:**

Ecojustice website <http://www.ecojustice.ca/>



## **Chapter 6: Teaching Notes**

### **The Bite of Blood Safety: Screening Blood for West Nile Virus**

*Helen Looker, David Reeleder, and Raisa B. Deber*

#### **Outcome**

After consulting with an expert committee, Health Canada and the Canadian Blood Services Agency ultimately approved the request to fund the Roche diagnostic test kit. Canadian Blood Services was already using other Roche NAT tests (for HIV and for hepatitis C) and so had the infrastructure in place to analyze Roche tests. The target was to screen all blood donors by July 1, 2003. Investigational Test Authorization (IND) was provided to the two blood operators (Canadian Blood Services and Héma-Québec) in the third week of June 2003; Canada-wide implementation of the test began July 2, 2003.

As of the October 2003 Canadian Blood Services board meeting, there had not been a single confirmed case of transfusion-transmitted West Nile infection in Canada, and only two cases had been reported in the US. In most of Canada, mini-pool samples (of six donated units) were tested. This approach was less expensive in terms of testing, but did not distinguish which of the samples in the mini-pool were infected, meaning that more donated units had to be discarded. In Saskatchewan, individual samples were tested on a precautionary basis, owing to the relatively higher rates of WNV in Saskatchewan and concerns expressed by the US Food and Drug Administration (FDA) about the sensitivity of the Roche test. Health Canada also raised a concern expressed by several provinces and territories about whether they could save money by only doing WNV testing during the summer months. In the December 17, 2003 Canadian Blood Services board meeting, Health Canada indicated that it would not change its directive for use of the screening test all year-round because there was still some, however small, risk of WNV transmission through blood from blood donors who might have traveled to endemic areas. Subsequently, in December 2007, Health Canada approved the medical device license application by Roche Diagnostics for their screening test to detect WNV in donated blood. Because Health Canada is the regulator of the blood supply, this meant that Canadian Blood Services was then required to implement this licensed assay.

The Canadian Blood Services website describes the protocol being used at the time of writing. In general, they tested mini-pools of 6 units. If one of these tests was positive, all six units were discarded, and all six donors would be deferred from giving blood again for 56 days (after which time they were no longer considered contagious). A positive test in a given region would trigger a switch to single-unit testing for the next seven days, as would a rate of infection in that region above a predetermined threshold (at that time 1 in 1,000 for rural areas, or 1 in 2,500 for urban areas). Single-unit testing, although considerably more expensive, was believed to be able to detect very low levels of virus in people who had just been infected, although the evidence was not yet strong. Canadian Blood Services also decided not to use “seasonal” testing (i.e., not testing for WNV in lower risk months); testing was performed year round.

According to the Canadian Blood Services website, since July 2003, every blood donation they had collected has been tested for WNV. As of September 30, 2009, this amounted to 6,038,452 units of blood tested. Of these, the number of infected donations found and discarded since July 2003 was 108; none of these had been found since April 1, 2009. They

further noted that, as of December 2009, 98 donors had been identified whose blood had tested positive for WNV since screening had begun in 2003.

Since the introduction of testing for WNV in Canada, Canadian Blood Services indicated that there were 14 units testing positive for WNV in 2003, 0 in 2004, 15 in 2005, and 8 in 2006. (Note that the use of mini-pools means that there may be some differences between the number of units discarded, and the number of units testing positive.)

Stakeholder reaction to measures undertaken by Canadian Blood Services to contain the threat from WNV infection in the blood supply was generally favourable. One Saskatchewan newspaper editorial had praised Canadian Blood Services for being “commendably on top of the West Nile file” through implementing the test so quickly; the cost was not discussed.

The Canadian Blood Services website quoted an August 2003 survey conducted by Ipsos-Reid for Canadian Blood Services, “eighty-three per cent of Canadians agree that the blood system in Canada is safer today than it was five years ago, and 74 per cent say that it is completely or somewhat safe to receive blood (up from 56 per cent in May 1998)” (Canadian Blood Services, 2003).

There were some slight changes in the players after the events of this case. In 2005 the Public Health Agency of Canada (PHAC) was established at the federal level. PHAC has taken on certain coordinating/advisory and informational roles previously housed within Health Canada, although PHAC is not involved with service delivery. Note that Health Canada does have a local service delivery role for particular populations under federal jurisdiction (e.g., First Nations and armed forces).

There have also been some efforts to improve the safety of transfusions within hospitals. Health Canada has worked on national safety guidelines on blood handling, and federal/provincial/territorial governments were implementing a transfusion transmitted injuries surveillance system (TTISS) to track and contain adverse events, as well as a Transfusion Errors Surveillance System (TESS). In addition, physicians have sought to improve the appropriateness of how blood products are utilized, often through the development and dissemination of clinical guidelines in combination with physician education. In some provinces, multi-disciplinary medical “gatekeeper committees” (including neurologists, pediatricians, rheumatologists, transfusion experts, and others), have been created.

### **Possible Points for Discussion:**

#### ***1. What are your options? What are the advantages and disadvantages of each?***

As noted in the case, Canadian Blood Services suggested a number of policy alternatives to mitigate WNV infection. Note that these were not mutually exclusive; all were in fact employed to varying degrees. These included:

a) Using “safe” blood from areas within Canada (e.g., Newfoundland) not expected to be affected by WNV infection. This was unlikely to be a general solution, since there was unlikely to be enough such donor blood available to serve the entire country, and because “safe” was a relative rather than an absolute concept. A related possibility was to “shift” blood regionally, taking into account incidence of disease, detection of human cases of infection, or results from bird infections as a proxy for human risk (for example, blood collections from one region could be temporarily shut down if human cases or significant clusters of dead birds were found).

b) Importing “safe” blood from the US. This was also problematic. Assuming that this blood was indeed safer (recognizing that much of the US blood was collected from people living

in warmer climates where mosquitoes would be active for a larger proportion of the year), there were also Health Canada regulatory barriers for use of blood, a biologic regulated by the *Food and Drugs Act*, from a foreign country. It was also noted that much of the “tainted blood” studied in the Krever Commission had come from US sources.

c) Investigating various modifications of screening using Nucleic Acid Testing (NAT), including: where to use single vs. mini-pool testing, differences between competing private sector testing kits, use of lower cost existing serological (antibody) screening, and confining testing to mosquito seasons.

d) Do nothing and hope that no epidemic would occur, or that sick donors would voluntarily refrain from donating.

**2. What evidence would you consider relevant to assessing Canadian Blood Services’ request? Discuss how different ways of framing the question might affect your response.**

At minimum, before deciding whether to test for a condition, as a decision maker you would like information about such items as the nature of the condition (including its severity, who it might affect, and the prevalence) and potential or available tests (including their costs and test characteristics); see Chapter 1, section 8.2 (Screening). A broader perspective would also seek information about alternative policy options. Information about how to implement would also be helpful, including issues of jurisdiction, who would pay, and who would be responsible for what. A very expansive view might look at the opportunity costs (what else might have been done with these resources), although in practice, this rarely occurs. In practice, however, decisions must often be made before all of the evidence is available.

In the case of WNV, at the time of the case there was good information about WNV and its possible outcomes. There was some limited information about the epidemiology of WNV infection and the likelihood that it could be transmitted through the blood supply (Hollinger & Kleinman, 2003; Pealer et al., 2003). In that connection, it is important to recognize that those receiving blood might be more at risk for severe consequences from WNV infection than would those being infected by being bitten by mosquitoes, precisely because blood recipients were more likely than the general population to be already seriously ill or otherwise immunocompromised.

Although the tests were still being developed, there was preliminary data from Health Canada and the US Food and Drugs Administration (FDA) and Centers for Disease Control and Prevention (CDC) regarding the test characteristics (including effectiveness and cost) of NAT-based genomics testing for WNV. There was also data about other NAT-based tests for other infectious agents (HIV, hepatitis C).

The way in which policy issues are *framed* can influence decision-making and implementation processes (see Chapter 1, section 3.4, Framing).

If WNV infection is framed as a risk to the blood supply, particularly given the legacy of the Krever Commission, it becomes difficult to decide that any action which might be helpful, even if only marginally, is not worth taking, particularly if the only risks or costs are financial. Arguing in terms of cost places a dollar value on human life; this is easy to dismiss by those who claim that life is priceless and argue that policies encompassing “zero tolerance” (of risk) should accordingly be adopted. Note that the program as implemented in the summer of 2003 resulted in 14 blood donors being deferred from donating in Canada. If zero risk is the standard, then detecting any number greater than zero would be seen as a policy success, warranting continued funding.

Another way of framing the issue, however, might be in terms of the precautionary principle (see Chapter 1, section 3.6.2, The Precautionary Principle).

**3. Discuss the precautionary principle as it might apply to this decision. Discuss the impact of previous policy failures (particularly, the tainted blood scandal).**

The *precautionary principle* derives from an ethical framework that stresses doing no harm. It would stress that, if there is any potential of harm, the wisest course of action would be to act as if that potential is real, and act to minimize it. The instructor might wish to note that the precautionary principle has been suggested as a key rationale for those wishing to protect the environment, on the premise that if one waited until all evidence were in, one might be faced with irreparable damage (Foster et al., 2000; Kriebel & Tickner, 2001; Wilson et al., 2003).

In his final report on SARS, Justice Campbell endorsed use of the precautionary principle throughout all health, public health, and worker safety systems in Ontario. He defined the principle as stating “that action to reduce risk need not await scientific certainty” (Campbell, 2006). Note that adopting this view would seem to require that policy makers be flexible and nimble, and adapt their policies as new information becomes available. However, if one applies the precautionary principle using a level of zero tolerance of risk, considerations of cost-effectiveness are not relevant. One point for discussion is whether the adoption of such a principle means a precedent for acceptance of all new technologies promising improvement, however small, regardless of cost.

The argument hinges on the extent of risk aversion, and a decision about what probability of a really bad outcome is deemed unacceptable. Framing this in terms of the “opportunity costs” would give a different picture. How many lives might have been saved if the same money were used in other ways? (Of course, there is no guarantee that the money would be used in those other ways.)

This leads to another question about whose costs and consequences matter: individuals or populations? How can policymakers best balance individual and societal interests? What is the relevant population being considered? An individual requiring blood would obviously prefer that it be safe. But if absolute certainty cannot be assured, how does one balance the risk of not having blood available (which may happen if there are not enough donors), against the risk of a potential infection? How much is it worth paying (from the public purse) to reduce risk and what of the interests of those who are deprived of the resources that might have been used in other ways? In the legal system, individual claims tend to triumph, often over the wider public interest.

In that connection, the “tainted blood scandal” and the Krever Report still influence policy (Krever, 1997; Picard, 1998). Note that the tainted blood scandal had been costly to those involved in the blood supply. The federal government paid compensation to most of those injured. The Red Cross pleaded guilty to distributing a contaminated drug and was fined \$5,000; it also agreed to pay \$1.5 million for two programs, a scholarship program for victims, and a National Medical Error Endowment at the University of Ottawa. Criminal charges against most but not all Red Cross employees were eventually dropped. In October 2007, Dr. Roger Perrault, then director of the Red Cross, was tried and acquitted on charges of criminal negligence causing bodily harm, with the final charges not dropped until January 2008. Particularly in the post-Krever era, it would be difficult to defend the position that a potential risk to the blood supply was allowed to exist because it was not cost-effective to mitigate it. Provincial/territorial (P/T) governments, Canadian Blood Services and Health Canada would find it difficult not to fund a NAT screening technology as long as it was framed as potentially protecting the safety of the

blood supply. Refusal would be even more difficult if that screening technology had already been recommended in the US by the FDA or CDC. Note that the current incentives place no value on ensuring that there is enough blood, merely on ensuring that the blood that they have is safe.

#### ***4. What is cost-effectiveness analysis (CEA)? How might it apply to this decision?***

An alternative framing is the logic of cost-effectiveness (see Chapter 1, section 8.1, Economic Analysis: Cost-effectiveness), which would argue that one cannot always assume the worst, and that the wisest course of action would be to compute expected costs and benefits and act to maximize expected utility (Gold et al., 1996).

As noted in Chapter 1 and in Appendix D to the case, cost-effectiveness analysis (CEA) compares the costs and consequences of different policy alternatives. The cost-effectiveness ratio that compares two alternatives, often called the incremental cost-effectiveness ratio (ICER), is calculated as the difference in costs between the alternatives (net costs) divided by the differences in outcomes (net effectiveness). The C/E ratio is essentially the incremental price of obtaining a unit health effect (measured in such units as dollars per quality-adjusted year of life expectancy). As shown in Appendix D, WNV screening (and indeed, NAT screening for HIV, or hepatitis C) generates extremely high costs per unit of benefit. In 2003, for example, it cost \$10 million to identify 14 possibly infected donors, for a condition that was unlikely to generate severe consequences in over 80% of those who became infected. Since 2000, an estimated \$35 million has been spent to implement a hepatitis C NAT screening test to detect or defer up to 1 additional donor from infecting the blood system; a similar cost and consequence is attached to supplementing standard serological testing for hepatitis C and HIV with NAT screening tests (HIV NAT screening was implemented in 1999). Although the cost-effectiveness for WNV screening appears slightly better, economic analysis would still conclude that the costs of WNV NAT screening are still extremely high compared to standard medical interventions (where \$50,000 per QALY is considered “good”).

#### ***5. Comment on the roles and responsibilities of: Canadian Blood Services; different levels of government, nationally and internationally; health providers; industry. How does this affect policy implementation?***

An additional complication arises because of how blood is funded. In effect, Canadian Blood Services asks P/T governments to fund whatever hospitals ask for. As will be noted below, that approach does not provide incentives for hospitals to justify their requests for blood products.

The Naylor Report, which examined the reactions to SARS (National Advisory Committee on SARS & Public Health, 2003), noted that public health policies in Canada are strongly affected by intergovernmental relations. The report argued that the existing allocation of responsibilities across various levels of government has led to considerable confusion as to who should be doing what, and that the resulting gaps and overlaps can endanger the public health of other jurisdictions, since infectious disease tends not to respect jurisdictional boundaries.

In the case of the blood supply, Wilson has discussed how the post-Krever governance structure, which was already in place at the time of the case, clearly allocated regulatory authority to the federal government. The powers given to the arm’s length Canadian Blood Services allowed it to respond quickly to new infectious diseases and introduce safety measures without having to get approval from any level of government. Wilson concluded that this

governance structure was highly effective in protecting the safety of the blood supply, but at the cost of efficiency. In particular, this model gave no financial disincentive for the federal government to introduce safety measures even when these precautions would not be seen as cost-effective. This may, or may not, be seen as a good thing, depending on one's views of the policy tradeoffs discussed above. Indeed, to the extent that the federal government's committees were making decisions that they did not have to pay for, some approaches to federalism might term it an "unfunded mandate" (Wilson, 2004, 2007; Wilson et al., 2004). Again, this may or may not be seen as appropriate, depending on the perceived importance of the safety measures.

**6. Who pays for what? What incentives are there for industry to develop new tests, and how can governments encourage rapid technology developments on the basis of new or emerging threats? What can governments do to protect themselves from manufacturers charging excess developmental costs? How can costs be controlled?**

Another policy issue is how to deal with innovation, including the prices that should be paid. Industry would note that they had to respond quickly; WNV NAT screening was commercially developed and implemented during a 9-month period, from September 2002 (when the need was identified by the FDA and CDC) to the initiation of testing in the US in June 2003. Note that only the Roche and GenProbe-Chiron NAT platforms were approved by the FDA, and that only the Roche product was subsequently approved by Health Canada. (This is relatively fast; most pharmaceutical products take far longer to move from discovery to regulatory approvals to reaching the marketplace.) Besides meeting the required screening sensitivity and specificity, the platform was automated and able to build on the existing Roche NAT platform at Canadian Blood Services. In the US alone, the market was estimated at \$200 million, providing an incentive for manufacturers to develop a test to conform to FDA requirements. Aside from the incentive of the marketplace, other incentives might include R & D tax credits, direct government subsidization, reduced regulatory burden, and reduced corporate risk through collaboration between government and the private sector with shared goals in mind (Abraham, 2002).

Another issue is what price should be paid. Unless potential payers can set (and enforce) preassigned cost structures as part of their request for proposal process, there are few avenues to ensure cost control. By definition, if innovators can obtain patents, there is no possibility of competition until that patent expires. If payers are required to purchase the product because it is deemed necessary, the only constraints are corporate responsibility, which has not proven to be a particularly effective method of containing costs in the past. Similar issues arise in pharmaceutical pricing.

**See also in Chapter 1:**

- 2.1.3 Federal vs. Unitary models
- 2.2.1 Federalism in Canada: *The Constitution Act, 1867*
- 3.4 Framing
- 3.6.2 The Precautionary Principle
- 6.3.1 Public Health
- 7.2 *Canada Health Act*
- 8.1 Economic Analysis: Cost-effectiveness
- 8.2 Screening



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**The following website may also be helpful:**

CMA: West Nile Virus in Canada [http://www.cma.ca/index.cfm/ci\\_id/3303/la\\_id/1.htm](http://www.cma.ca/index.cfm/ci_id/3303/la_id/1.htm)



## Chapter 7: Teaching Notes

### Looking for Trouble: Developing and Implementing a National Network for Infectious Disease Surveillance in Canada

*Christopher W. McDougall, David Kirsch, Brian Schwartz, and Raisa B. Deber*

#### Outcome

The SARS virus was determined to have originated in animal populations in Guangdong province in China, passed to humans through the food chain in 2002 and resulted in human to human transmission soon after. SARS claimed about 800 lives worldwide, but the virus disappeared almost entirely within a year. While speculation as to the reasons for this rapid emergence and departure is beyond the scope of this case, these events illustrate how unpredictable emerging infections can be in their origin, virulence and impact (both on human health and society at large), as well as the importance of rapid detection, data collection, analysis and dissemination, and of a coordinated global response.

Progress toward a national surveillance system in Canada that would connect local, provincial/territorial and federal public health authorities and health care providers has remained slow. The listeriosis outbreak of 2008 again demonstrated how far Canada was from achieving a national surveillance system. As noted in the case, the International Health Regulations (IHR) required that all events that might be of international concern must be reported to the WHO within 24 hours; states had to assess their national systems and be in full compliance (linked electronically to a national operations centre) by June 2012. Although there was a stated commitment by Canada to comply with the IHR, at the time of writing the issue had not attracted much federal leadership or provincial collaboration in moving the process forward. Canada did hold a National Roundtable in April 2010 with the objective of developing a plan to address these issues through the provinces and territories to strengthen Canada's capacity to meet the IHR obligations, but this had not yet happened at the time of writing. Although the PHAC 2012–13 *Report on Plans and Priorities* posted on their website indicated that their target for compliance with the surveillance regulations was March 31, 2014, the 2013-14 report made no specific mention of such targets, and instead noted “Budget 2012 savings measures will streamline surveillance activities and publications without affecting program delivery.”

However, there has been some progress on related issues. In the wake of the SARS crisis, Canada Health Infoway was provided with an additional \$100 million funding for the development of a Pan-Canadian CD surveillance framework, known currently as Panorama. Infoway issued a Request for Proposal (RFP), awarded to IBM, to develop the platform. However, its functioning requires provinces to pay for and use multiple modules (most importantly, the Communicable Disease Case Management and the Outbreak Management modules), and some provinces have claimed that they cannot (and will not) pay the costs of implementing all of those modules without significant federal financial assistance. At the time of writing, uptake of the Panorama Notifications and Alert module, the main rationale for the program, was still limited. Each province is responsible for adding the capabilities they need and can pay for (since the system requires recurring annual licensing, operations and maintenance costs to IBM), and for providing infrastructure and ensuring that the data is entered. Ontario put

a temporary hold on the project in 2009, but in March 2011 announced a phased roll-out of all modules to be complete by 2014. BC has also signed on and Quebec will likely follow suit. However, at the time of writing, the Public Health Agency of Canada (PHAC) was not using Panorama, because it was seen as too expensive, and it did not appear that there would be 100% buy-in from all of the provinces. This meant that a fully integrated, operational Canadian solution would not exist. Since the platform contains an immunization registry, vaccine management, and case management features, some benefits will accrue even if various provinces do not implement all features, because data will be entered from the three largest provinces in Canada, each of which also houses a public health agency. As a result, information about over two-thirds of Canada's population will still be available, easing the ability to comply with IHR.

### **What are the Policy Alternatives?**

Your province may choose to: implement the entire framework, implement parts of the framework, or continue to use the current systems. It may also choose to enhance its current system (e.g., Ontario's Integrated Public Health Information System, iPHIS), in cooperation with the other provinces.

The major factors to consider involve costs, technical expertise, and the need for coordination. Questions might include: Is there enough will, money and momentum to implement across Canada? What are the real out-of-pocket expenses? Will other provinces commit the required resources? Would the money be better spent elsewhere? Can the federal government be persuaded to provide additional funding? Will the other provinces implement the framework? Will technical implementation difficulties significantly increase implementation costs? Can standards be developed to ensure similar use of the system in the various jurisdictions? Will implementation delays result in payments not being made by Infoway?

A number of (not mutually exclusive) options for mitigating the risks exist, including: a) obtain commitment for all funding prior to proceeding; b) provide contingency for implementation overruns; c) obtain commitment from all provinces to implement the core functionality; and/or d) create a single nationwide development and implementation team to build, configure and deploy the core functionality, and provide uniform training. These require a degree of cooperation that may or may not be forthcoming.

Note that most discussions of public health surveillance assume that privacy concerns are less important than ensuring that infectious diseases do not spread. The class may wish to consider what sorts of privacy protections are warranted, and what differences might arise if surveillance is extended to other conditions, including chronic diseases, adverse drug effects, and so on.

### **Possible Points for Discussion:**

***1. If you were building a surveillance infrastructure, how would you connect, and ensure compliance from, all sources of information (physicians and other primary care providers, hospitals, laboratories, local, provincial and federal public health units) so as to ensure a robust, accurate, and usable system?***

Public health surveillance is defined as "the ongoing systematic collection, analysis, interpretation and dissemination of data about a health-related event for use in public health action to reduce morbidity and mortality and to improve health" (German et al., 2001). Experts argue that an ideal surveillance infrastructure must be electronic, usable and accessible. Primary

users such as physicians, laboratories and hospitals should be able to input data easily and not have to “double enter” data that has already been stored in a patient record. It should be accessible, but compliant with applicable privacy legislation. Public health authorities at the local, provincial/territorial and federal levels should all be able to access the data as necessary and appropriate in order to analyse and conduct investigations, communicate with other jurisdictions and measure the effect of clinical and public health interventions (e.g., antiviral treatment, vaccines) and public health measures (e.g., hand hygiene).

An additional complication is that there are differences across subsectors in how surveillance is implemented. For example, in Ontario, physicians, laboratories and hospitals are required by the *Health Protection and Promotion Act* to report information on designated reportable diseases, but this information is limited to the person’s name, address and the disease. Clearly, this legal requirement would often not provide enough information to conduct surveillance for the purposes noted above. Provinces/territories may choose to go further. For example, Ontario has required local PHU staff to enter such data into iPHIS; one goal is to ensure that provincial/territorial data can in turn become part of a national dataset, although this is still not fully realized.

Progress is being made on a condition-specific basis. For example, at the time of writing, selected Ontario physicians were participating in a *sentinel physician surveillance network* for influenza, connected to laboratory services and PHUs, which provides more detailed information on patients who present to these providers with influenza related illness; this network can help produce a national perspective on the incidence, target populations, viral “fingerprint”, clinical aspects and vaccine effectiveness related to seasonal and pandemic influenza.

Note that different policy levers can be used to ensure compliance by different stakeholders for different activities (see also Chapter 1, section 5.2, Policy/Governing Instruments). Some (including the sentinel physician surveillance network) use financial incentives. Other possibilities include regulatory approaches (including legislative requirements). It is less clear who would/should ensure that the appropriate combination of legislative requirements and financial incentives are put into place; given constitutional constraints, this could involve memoranda of agreement among the provinces/territories and PHAC, although enforcement could also be an issue.

***2. Should Canada adopt a more centralized approach to public health? What would a more centralized approach look like? What are the advantages of such an approach? What are the negative impacts of such reforms, and how would they be managed?***

The answer depends on what type of centralized approach is considered, and how important it is to preserve provincial and local autonomy in these areas. Coordination with other sectors of the health system (including physicians, other primary care providers, laboratory services) and other non-health actors such as local food services, waste management and small drinking water systems (the “bread and butter” of public health activity), often work best at local or regional levels. For example, of over 2000 outbreaks monitored and managed yearly in Ontario, only a small fraction cross jurisdictional boundaries even within the province. However, those outbreaks that do cross jurisdictional borders may present major problems.

Federal requirements that require provincial/territorial governments to bear the costs can be described as an “unfunded mandate”, and may generate conflict among levels of government. Policies that force independent providers to comply with government regulations are also dependent on who has what legal authority. A number of examples where the federal

government initially sought consensus, but stepped in with firmer rules when collaboration proved inadequate, have been described by Wilson and Lazar as *coercive collaboration* (Wilson & Lazar, 2008).

Rather than work through PHAC, the Federal government has provided funding to Canada Health Infoway (Infoway) to accelerate the implementation of electronic health information systems in Canada. Consistent with its mandate, Infoway provided \$100 million for the creation of a Pan-Canadian framework for communicable disease surveillance and management. In order to implement the framework, each province expects to incur costs of the same order of magnitude as the initial investment. Infoway may fund up to 25% of these costs. Without full funding from the Federal government, it is unlikely that all of the provinces will implement the framework. Although there will be some benefits derived from implementing the framework in some provinces, public health experts have argued that full value to Canada can only be realized if it is implemented in all provinces. However it should be noted that the total cost of implementation across Canada would likely be in the \$600 million to \$1 billion range, which is still much less than the costs incurred by Ontario from one outbreak of SARS.

***3. If the present system is maintained, how can Canada ensure compliance with the International Health Regulations while maintaining decentralized approaches to public health? What are the policy options? Is the reservation the government of the United States submitted to the WHO (see Appendix D) relevant to Canada? Why or why not?***

As noted, a centralized hierarchical approach is not consistent with the Canadian constitution, which gives responsibility for most health care matters to the provincial/territorial governments. If the provinces/territories are willing to voluntarily enter into a collaborative surveillance framework (with one possibility being a memorandum of agreement supported by funding arrangements), suspected events would be entered into the electronic system. These data, with personal information not relevant to the reporting requirements removed, would then be available to other provinces/territories and the federal government. Public health workers would have full access to the cases and be able to provide appropriate assistance and advice. Guidelines could be established in the electronic system to send alerts based on the data entered by local providers/public health authorities, or all events could be automatically forwarded and provided on a management dashboard. Since relevant actors would have access to each event, provincial and federal involvement could be initiated at any level, and there would be an early warning of a potentially significant event. International notification could be established electronically, or, if this was seen as infringing on Canadian sovereignty, other processes could be established. The system could be designed so that local units could flag an item to be of local interest only, but the provincial and federal governments would still have access to the events and would be able to follow-up with the local PHU. However, this might add a burden of legal liability for outbreak management to the provincial and federal governments, so appropriate policies would need to be established.

Since potential events are identified locally and escalated based on ongoing findings, it may be possible to report provincially within 24 hours of finding a confirmed event of potential international importance. If this is not possible or is inconsistent among jurisdictions, in a worst case scenario, failure to report on a timely basis could potentially result in a significant worldwide increase in morbidity or mortality as a result of the event.

The reservation submitted by the United States is relevant to Canada, but this reservation appears to seek to avoid the real issues that IHR is supposed to address rather than deal with

them; the US government is instead disavowing its accountability based on its interpretation of the principles of federalism. In Canada, compliance is also dependent on agreements at all levels of government to share surveillance data, and define what minimum datasets need to be reported up and down the chain. These processes, as outlined previously, are interdependent and if one level cannot demand cooperation, they require a measure of collaboration. If this is not forthcoming, and/or if the necessary information technology tools are not in place, Canada may be in a similar position as it was during SARS and would not have the capacity to inform the WHO and to meet its international obligations.

***4. What should Canada's foreign policy be in terms of global surveillance support? What are the issues and what is the return on investment on supporting less developed countries? What are the risks?***

During the fifth and sixth centuries the bubonic plague killed approximately 50% of the population in the area between the Middle East and the Mediterranean basins. A pandemic in Europe between the 8th and 14th centuries killed nearly 40% of its population. The Black Death, another bubonic plague, resulted in the deaths of an estimated 25 million people between 1347 and 1352. The Spanish Flu of 1918-1919 resulted in an estimated 20 to 40 million deaths. These events would suggest that it is essential to treat surveillance as a matter of critical national concern and to put in place the policies that will minimize risk to the public. On the other hand, some potential pandemics did not materialize, which presents the danger of being seen as the boy who cried wolf.

Another issue is the perceived exploitation of developing countries. In 2007 Indonesia refused to commit to sharing virus samples for H5N1 (avian influenza, predicted at that time to be the likely agent for the next influenza pandemic) with the WHO, unless a commitment was forthcoming from the WHO that vaccine produced from these samples would be made available to its own citizens after commercialization of the vaccine. Experts have noted that Canada, along with other industrialized countries, has a global responsibility to explore ways to ensure that more of the world's people have access to vaccines when the next flu pandemic hits. The WHO and its wealthier members are under pressure to find creative and globally responsible solutions to these issues. However, during the 2009 H1N1 outbreak, Canada was conspicuous in its refusal to go along with an announcement by a number of other G20 countries that they would share a rolling 10% of their vaccine allocations with poorer countries unable to afford them.

The risks to international support include financial costs as well as public perception, particularly in times of fiscal restraint, that money is being spent offshore when it could be "better put to use" on national or provincial programs. These criticisms can be short sighted when viewed through the lens of a global village, where SARS arrived in Toronto on an airplane from Asia and demonstrated that an epidemic starting in one country could easily spread around the world in a matter of hours. Beyond the altruistic goals of assisting less developed countries in reducing deaths and illness from a communicable disease, there is likely to be a considerable return on investment from prevention, mitigation or delay of arrival of an epidemic of what may be an emerging health threat due to a heretofore-unknown infectious agent. However, prevention is invisible, and it is difficult to identify, let alone cost out, outbreaks that never happened. This is a perennial problem for public health in competing for resources with problems that treat, rather than prevent, illness.

***5. What are the ethical implications of surveillance for emerging infectious diseases such as SARS and novel strains of influenza? How do these differ from the ethics of screening and testing for other infectious diseases (eg: HIV, tuberculosis, or syphilis) and for noncommunicable diseases (such as obesity, or the various cancers and genetic disorders for which testing currently exists)?***

As noted in Chapter 1, section 3.6 (Ethical Frameworks), many of the ethical considerations arise from the priority that bioethics places on the protection of individual autonomy. These approaches are often less suited for matters affecting public health. One key distinction is that public health must often deal with risks and benefits at the international, national, and community levels, rather than focusing only the implications for the health of individuals. A related consideration, linked to discussions of equity, is the extent to which social and economic causes of disease may in turn affect the risk of mortality and morbidity, especially from infectious diseases. For example, poor and crowded housing conditions may make it easier for diseases to spread. One attempt to deal with these trade-offs is the emerging sub-field of public health ethics (Childress et al., 2002; Gostin, 2007; Tausig et al., 2006). The US Centre for Disease Control (CDC) has set up a Public Health Ethics committee; in an unpublished document, they indicated their desire to develop a systematic process, combining scientific evidence, ethical principles, and the values and beliefs of key stakeholders, to help to clarify, prioritize and justify possible courses of public health action. One emphasis is the need to minimize potential intrusion on individuals. The class may wish to discuss how far such justifications might extend. For example, how much surveillance would be appropriate to identify adverse reactions to prescription drugs, or is ensuring the privacy of those taking those medications more important? To what extent would public health arguments justify attempting to modify the diet and lifestyle for those populations at greater risk of chronic diseases? Public health ethics is focusing on how to promote public trust, solidarity, and social justice, and how to balance this against measures that clearly restrict liberty and privacy (albeit for a public benefit), including contact tracing, travel restrictions, quarantine, and mandatory treatment and/or prophylaxis (Verweij, 2011).

Since timely and detailed data is needed for effective infectious disease surveillance, most countries have chosen to legally require notification of cases of certain infections, as well as performing routine screening for others (e.g., most Canadian jurisdictions screen for HIV and hepatitis B among pregnant women). These policies raise questions of confidentiality, as well as of voluntary informed consent. In some cases, this is dealt with through such measures as allowing people to opt-in (or opt-out); in others, the potential hazard is seen as sufficient to require all to participate. Other troubling empirical and social issues may be related to who will get the results, and how policy deals with false positives and false negatives (see Chapter 1, section 8.2.2, Assessing Screening Tests). Different tests will have different costs and will also vary in accuracy. False negative results may allow disease to spread, but positive results (whether false positives or true positives) can dramatically affect an individual's employment and insurance options. Outbreaks of infectious diseases can lead to panic, stigmatization, and economic hardship for individuals and communities. Preventing further spread of disease may require closures or quarantines; these create still more burdens, and raise such issues as whether and how to compensate those who incur losses as a result of efforts to protect the health of the community (e.g., industrial livestock losses during BSE or avian influenza, loss of profits and wages if businesses are closed). Such burdens may fall disproportionately on the most vulnerable. Similarly, there may be difficulties in ensuring that vulnerable populations adhere to



treatment regimens; one example is trying to ensure that a homeless individual can afford and complete the 24 month long antibiotic treatment for drug resistant tuberculosis (TB).

Public health ethicists currently argue that the moral justification of public health interventions to control infectious disease rests on at least three considerations. First is the likelihood and magnitude of harms to be averted; the more irreversible, untreatable or lethal the infection, the more public authorities are justified in infringing on individual rights, if need be to the point of compulsory interventions. Second is their judgment of the effectiveness and feasibility of the proposed measures for controlling the potential outbreak. Third is their view of the proportionality of the proposed intervention, which refers to the balance of the likelihood of harm and effectiveness against the available alternatives. This would suggest that the most intrusive measures would be justified only in an emergency (or potential emergency) or when alternatives have failed to protect against the risk of further spread of disease.

One effort to specify how such considerations might apply to infectious disease control, based on the experience of SARS, was undertaken in a multi-stakeholder report, *Stand on Guard for Thee* (SOGFT) (Upshur et al., 2005). The SOGFT report includes descriptions of ten *substantive principles* (individual liberties, protection of the public, stewardship, trust, solidarity, proportionality, privacy, duty to provide care, reciprocity, and equity) and five *procedural values* (inclusiveness, responsiveness, accountability, reasonableness, and transparency) that taken together provide a framework for identifying, evaluating and balancing ethical considerations in outbreak planning and response. McDougall has surveyed other frameworks and decision-making tools and guides for the integration of ethical analysis into outbreak planning and response (McDougall, 2011a) and compared the ethics-related content and recommendations of a cross-section of regional, national, and international pandemic influenza plans (McDougall, 2011b).

The SOGFT report has since been integrated into a variety of national and international pandemic influenza plans, including the WHO's *Ethical considerations in developing a public health response to pandemic influenza* (World Health Organization, 2007) and PHAC's 2006 *Canadian pandemic influenza plan for the health sector* (CPIP). The text of the CPIP proposes six ethical principles in support of two main goals "to minimize serious illness and overall deaths, and to minimize societal disruption among Canadians as a result of an influenza pandemic". The principles are to: 1) protect and promote the public's health; 2) ensure equity and distributive justice; 3) respect the inherent dignity of all persons; 4) use the least restrictive means; 5) optimize the risk/benefit ratio; and 6) work with transparency and accountability (Public Health Agency of Canada, 2006).

Note that these frameworks and plans are not without criticism, particularly from various philosophical and feminist traditions that find fault with what they see as the privileging of an individualistic focus, at the expense of social justice. For example, some have argued that independent personhood and rational autonomy are fictions, and that the decisions people make are profoundly marked by their social relations and the options available to them (Baylis et al., 2008). Battin et al. (2008) make a similar point when they argue for the view that all patients with infectious disease are both and inseparably victims and vectors, and are as inextricable from biological "webs of disease" as they are from social networks and obligations. Such views bring to the foreground some potentially problematic assumptions about infectious disease control, including the limited ability of certain (generally marginalized) groups to take protective precautions (such as social distancing and hand washing recommendations for people/communities with no or limited access to alternative living spaces or clean water) and the

pragmatic feasibility of certain common strategies to disrupt transmission (for example, requiring families with children of different ages to make multiple trips for influenza vaccination based on age-defined priority sequencing lists). For an example of a pandemic plan that takes a more communitarian approach, see the New Zealand National Ethics Advisory report *Getting Through* (Moore et al., 2007). However, the issue of minimizing the risk to other members of the community remains. As is often the case when dealing with tradeoffs, there is no one clearly correct answer.

### See also in Chapter 1:

- 2.1.3 Federal vs. Unitary Models
- 2.2.1 Federalism in Canada: *The Constitution Act, 1867*
- 3.5 Public Goods and Externalities
- 3.6 Ethical Frameworks
- 5.2 Policy/Governing Instruments
  - 5.2.1 Regulation
- 5.5 Globalization
- 6.3.1 Public Health
- 7.1 Financing Health Care in Canada: Fiscal Federalism
- 8.2 Screening
  - 8.2.2 Assessing Screening Tests (test/truth)
  - 8.2.3 The Role of Prevalence

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**The following website may also be helpful:**

Public Health Agency of Canada:

Reports on Plans and Priorities are posted at: <http://www.phac-aspc.gc.ca/rpp/>

Surveillance programs are given at: <http://www.phac-aspc.gc.ca/surveillance-eng.php>



## **Chapter 8: Teaching Notes**

### **Filling in the Gaps:**

#### **The Decision to Utilize Agency Nursing in Tarman Hospital**

*Karen Arthurs, Andrea Baumann, Doreen Day, Sarah Dimmock,  
Leah Levesque Eleanor Ross, Vera Ingrid Tarman, and Raisa B. Deber*

#### **Outcome**

This is a hypothetical case, without a specific outcome.

#### **Possible Points for Discussion:**

##### ***1. What would you do if you were Ms. Arthurs? What if you were a part of the Hospital Management Committee? Why?***

As suggested in the case, several options might be considered. The class might also note that these are short-term approaches, and that another option is to focus on improvements to recruitment and retention practices in the hospital, including innovative scheduling and reduction of absenteeism, in order to meet staffing needs (see also Chapter 1, section 8.4, Health Human Resources).

As noted in the case, the language in some of the collective agreements with nursing unions is restrictive with respect to the number of night or weekend shifts that a nurse can work. In combination with the province's requirement that at least 70% of the nursing staff in the organization be full-time (FT) hires, there is likely to be a shortfall in shift coverage unless there is a full complement of part-time nurses or float positions to support and backfill for the FT nurses. However, in spite of the limitations in scheduling permitted by the collective agreement, there is language that permits weekend workers and "innovative scheduling". At some hospitals, there has been success at creating weekend worker positions and in the creation of FT float positions in order to better cover the units. The weekend workers are paid a premium (work 60 hours for 75 hours pay), but some hospitals have concluded that this was a worthwhile investment. In addition, the creation of FT float positions has been accepted by the union with the commitment that the nurses will be guaranteed a "home" unit (approximately 0.4FTE) and will be given appropriate training to be competent in other units. In some cases, part-time vacancies are combined to create one or more FT positions.

Investment in recruitment and retention has included such measures as the addition of Human Resources staff devoted to nursing recruitment. In the longer term, some hospitals have focused on increasing the number of nursing students who do placements at their organizations, and building relationships with the Schools of Nursing at various universities to increase the hospital's profile among future nurses.

All the hospitals that have successfully reduced agency use have done so in part with a structured attendance management program that addressed the issue of absenteeism. In particular, it is important to minimize injury and sickness rates. The attendance management programs have often included developing or outsourcing an Attendance Management program that has multiple phases and such elements as established triggers for case management, follow-up as needed, and disciplinary action as appropriate. These organization-wide programs have

been beneficial in several ways. By being completely transparent, they have allowed the unions and the employees to understand the triggers and consequences for absences. This has been supportive to the Program Managers, who can be seen to be following an established protocol rather than being perceived as being “hard” on people or “unfair”. It also sends the message that such actions are corporate programs, driven by the leadership, with established targets and goals that everyone is accountable for meeting.

Another option is to examine the skill mix, which might include an expanded scope of practice for LPNs and more use of such unregulated workers as personal support workers (PSW), or health care aides (HCA). This option is not a new one; in response to shortages during the Second World War, new classifications of care providers had been introduced, including nurses’ aides. The titles, required preparation, and scopes of practice have changed over time. For example, in Ontario LPNs are called Registered Practical Nurses (RPNs); that title dates from 1993 and reflects the increased competencies expected of what used to be called nursing assistants. Prior to 2005, RPNs required orders to carry out certain functions that fell within the scope of practice of RNs. In 2005, the educational requirements for RPNs were changed, and the province’s *Nursing Act* was amended to allow RPNs to initiate certain controlled acts, such as dressing changes and catheterization. Ontario RNs and RPNs now have identical authorized acts.

Being unregulated workers means not only that neither PSWs nor HCAs are regulated by a college or regulatory body, but also that there is no national certification exam or mechanism to ensure that all unregulated workers have the same level of knowledge or skill. Hospitals are therefore reliant on the ability of the RNs to delegate the duties that the unregulated workers are able to perform. One of the concerns identified by the nursing staff is their increased responsibility and accountability for patients who are receiving care from these unregulated workers. This policy has been reported to have resulted in increased dissatisfaction for the nurses, recruitment and retention problems in some hospitals.

Another option is to hire a greater proportion of FT nurses. Indeed, Ontario had developed a policy (the 70% solution) to encourage hospitals to ensure that 70% of their nursing staff were FT. This policy has been strongly supported by the Registered Nurses Association of Ontario (RNAO), although it does not always reflect the fact that many nurses would prefer to work regular PT shifts than to work FT, particularly when they have family obligations. Should this approach be taken, administrators would have to ensure that there were sufficient funds in the budget to cover the costs of hiring more FT nurses, including providing benefits. In determining whether they considered this strategy to be cost-effective, it would be important to take into account the other organizational costs and benefits of using FT staff versus agency staff. As noted in the case, these could include having to pay for staff education, and the benefits incurred by having a staff that understands the organizational culture, procedures and policies of the organization.

However, having a 70% FT nursing staff does not necessarily guarantee that there will be staff available to cover shifts when needed, particularly when one has to cover sick time, vacations, and surge capacity. Management/administration would therefore want to consider the skill mix of the staff that are being hired in order to ensure a good mix of skills and the flexibility to be able to move staff across departments and units when needed. Indeed, if funds were available, management might want to *overstaff* the unit to have a built-in buffer to cover surge capacity and unpredictable shortages.

Another possibility is to close beds when the staff is not available, rather than use agency nurses. This approach is likely to be met with great concern by the physicians who treat patients

in those units, by the public, and by the government (who might argue that they were funding hospitals and expected them to serve their patients). In the 1990s, when hospital budgets were highly constrained, some hospitals did close beds; the media was often scathing towards the hospitals who chose this route. Particularly with higher health care budgets and a policy of encouraging FT nursing employment, bed closure is unlikely to be well received.

## ***2. What affects work satisfaction? How might this apply to nurse satisfaction in hospitals?***

In the 1950s, Herzberg developed a theory of compensation (Miner, 2005). It asserts that the return of rewards from work can be divided into two sets of factors, which he termed hygiene factors and motivating factors. *Hygiene* factors are extrinsic factors found in the work environment, such as working conditions, the supervisors and co-workers. *Motivating* factors are those found intrinsically within the work content, including autonomy, control, and power. Most of the recent studies on nursing satisfaction point to issues falling into the category of motivating factors, particularly such issues as lack of autonomy and control. In contrast, pay would be deemed a hygiene factor; depending on how it is managed, it could increase or decrease dissatisfaction. Nursing salaries are often determined by pay scales negotiated by employers and unions, and are not tied to performance as much as to years of service to the organization.

The class may wish to discuss why (and whether) nurses are discontented with hospital work. As noted in the case, there are a number of potential irritants (including shift work). However, Alameddine et al found that nurses were very likely to remain in their profession, and indeed, that they were more likely to remain in hospitals than in other sub-sectors (Alameddine et al., 2005; Alameddine et al., 2006). The arguments about nurse dissatisfaction have been effective at attracting more resources, but may or may not be supported by the data, which in general demonstrates that most nurses really like their work.

## ***3. Discuss the implications of different models of nursing care, including the use of unregulated workers to perform nursing tasks. What role does professionalism play?***

As noted in Chapter 1, section 6.4 (Professionalism), one defining aspect of a profession is that they have specialized knowledge, and perform tasks whose quality can only be assessed by those with that specialized knowledge. For that reason, professions tend to be self-regulating (Freidson, 1986, 2001). The extent to which nursing is recognized as an independent profession, rather than being viewed as a “physician’s handmaid”, has also varied across jurisdictions and over time. One question is the extent to which only members of that profession can judge the quality of the services they deliver, or whether other providers can also evaluate the standard of care. In some provinces, including Ontario, this has been partially dealt with by regulators through the concept of “controlled acts” that can only be performed by designated health professionals. In a team-based environment, where others are observing the care delivered by each provider, it is also easier to build in protections against poor practice. In contrast, it is far more difficult to evaluate the quality of care delivered by providers practicing on their own, such as a home-based nurse, or a physician in a private practice. Under such circumstances, there is greater reliance on the inherent professionalism of the provider, as reinforced by their professional colleges.

*Scope of practice* refers to the roles, responsibilities, functions and activities that health human resources (HHR) are authorized to perform. Despite different educational backgrounds, there is significant overlap between scopes of practice of RNs and LPNs, as indeed, there may be overlap between the scopes of practice of physicians and nurses.

To the extent that there is a shortage of nurses, hospital administrators have had to look at alternative solutions which may include expanding the role of LPNs and the introduction of unregulated workers into the hospital work environments. Many aspects of physical care can be provided by a variety of health care providers, which includes RNs, LPNs, and unregulated workers. Other aspects cannot. One of the challenges identified is to determine what aspects of care can be safely provided by other care providers. In response to such concerns, the provincial College of Nurses of the province where Tarman Hospital is located developed two sets of guidelines for employers and nurses to assist with decision making in determining what they consider to be the appropriate use of unregulated workers. Clearly, this will vary with the sorts of care being provided.

***4. Who are agency nurses? How are they used? What are the advantages and disadvantages of using agency nursing? For nurses, unit managers and staff? What are the potential implications for: Costs? Patient safety and quality/continuity of care? Nurse morale?***

Some advantages and disadvantages of agency nursing are discussed in the case. Many years ago, nurses were autonomous, self-employed and worked in patients' homes. With increased medical knowledge, much care moved to hospitals, and nurses became hospital employees. At the time of writing, most nurses were salaried employees who worked in a variety of settings, including hospitals, home care, public health, physician offices, and industry (occupational health and safety). One key issue is the balance between generic skills that can be deployed in any setting, and skills specific to a particular workplace. In the case of nursing, one could view this as necessary but not sufficient; one would need the skills possessed by RNs, but also an understanding of the systems within specific settings that may vary across workplaces.

As noted in the case, one can look at the hourly costs of various staffing alternatives, although Table 8-1 may not capture the hidden costs of FT staff (e.g., benefits, in-service training) versus the hidden costs of agency staff (e.g., orientation, duplication of functions, agency profit). In terms of costs, although the agency rates are higher, once one includes fringe benefits, the agency nurse may have a similar cost to staff nurses (depending on the experience of the staff nurse and the rate she must be paid). There are also opportunity costs in not using staff nurses, particularly regarding quality improvement and recruitment and retention. These issues may also apply to casual nurses, who may also not be well integrated into health teams.

One approach widely used to analyze quality of care looks at three components, which are often called structure, process, and outcome (Donabedian, 1988).

The *structure* dimension refers to the physical capabilities and resources of the hospital. One concern hospitals have is that they cannot control the qualifications of agency nurses; they basically take whomever the agency sends. Although hospital managers cannot guarantee the standards of agency nurses, agencies do have hiring standards and performance evaluations and are increasingly likely to be accredited (although these standards may differ between agencies). To the extent that agency nurses are younger than their staff nurse counterparts, however, they may be more likely to hold baccalaureate or higher degrees, which can be an advantage. Regulatory bodies have also stepped in. For example, in Ontario, the College of Nurses of Ontario now holds the staffing agencies responsible for ensuring that the nurse is registered with the College and qualified to meet the needs of their temporary employer. Another approach has been employed by the US Joint Commission on the Accreditation of Healthcare Organizations, which has developed a program for certifying excellence in staffing companies that evaluates the credentials and competencies of staff.



The *process* component of quality refers to the evidence relating to the provider's activities. This refers to level of in-service training, quality of the working environments, and continuity of care. In the same way that hospitals are unable to control the qualifications of agency staff, the hospitals can not control the amount of continuing education those nurses receive, which may also vary across agencies. Some agencies offer in-service seminars on such topics as care for the aged, or stress in the work place, while others may offer little more than CPR. Agency nurses are less likely to be familiar with an individual hospital's procedures, policies and setting, although they are likely to meet expectations regarding actual patient care.

*Outcomes* can also be assessed; particular attention has been paid to adverse outcomes associated with errors (e.g., medication errors, infections, and/or falls). Ideally, focus would be on outcomes that are nursing sensitive. One possibility is that Ms. Arthurs could seek to use the same agency, or even insist on the same nurse, or ask for a certificate of competence.

Other questions might involve how to ensure that there were not adverse implications for nurse morale.

### See also in Chapter 1:

- 5.2.1 Regulation
- 6.3.2 Sickness Care Subsectors
- 6.4 Professionalism
- 7.3 Regulating Health Professionals
- 8.4 Health Human Resources

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## **Chapter 9: Teaching Notes**

### **Midwifery: Special Delivery**

*Karen Born, Carole-Anne Chiasson, Shawna Gutfreund, Lisa Jackson, Esther Levy, Judy Litwack-Goldman, Elizabeth McCarthy, Wendy Sutton, Betty Wu-Lawrence and Raisa B. Deber*

#### **Outcome**

As noted in the case, almost all provinces have chosen to incorporate midwifery into their health care systems and to regulate it. However, there is considerable variability in whether their services are publicly paid for, how their practices are organized, and where they deliver care.

#### **Possible Points for Discussion:**

##### ***1. Discuss the advantages and disadvantages of midwifery. What might this depend on?***

Attempts to analyze midwifery have focused on various combinations of costs, access, quality, and patient preferences. One helpful source is a series of reports on giving birth in Canada produced by Canada's Canadian Institute for Health Information (CIHI).

As noted in the case, a variety of professionals can assist with birth and delivery. In general, midwives cost less, particularly for uncomplicated home births. There are several reasons. Physicians receive higher fees than do midwives, and home births do not need to cover expensive hospital overhead. Treatment by midwives also tends to be less aggressive. In 2002-2003, CIHI estimated that the average inpatient hospital costs (excluding physician/midwife fees) for patients who had a vaginal delivery with no complications were about \$2,700, rising to approximately \$4,600 if the woman had a caesarean delivery (Canadian Institute for Health Information, 2006). Note that costing depends on what is/is not included in the analysis, but the patterns remain consistent. According to the Association of Ontario Midwives, a 2003 review performed by the Ontario Ministry of Health found that each midwife-attended birth saved the system \$800 if delivery was in a hospital and \$1,800 if it was at home. The estimated savings primarily resulted from less aggressive therapy: c-section rates were 30% lower for midwifery patients than for family doctors; episiotomy rates were less than half; readmission rates to hospital were 65% lower; and hospital stays were shorter. Midwives also provided community care, resulting in less reliance on inpatient services. An additional longer-term benefit was that there was a 91.5% breastfeeding rate for babies whose birth was attended by a midwife (Association of Ontario Midwives, 2012).

However, initial cost is an inadequate criterion. The goal is a healthy child and a healthy mother. Even from the viewpoint of economic analysis, if the outcomes are worse, long-run costs are likely to be far higher. Comparisons also were hindered because those women using midwives were unlikely to be a random sample of the population. As one example, to the extent that those women choosing midwife-assisted home births would also be more likely to decide to breastfeed, correlation would not be causation.

From the viewpoint of access, family physicians are increasingly unwilling to include birth and delivery within their practice. Other causes of concern relate to the extent that the workforce doing births and deliveries is nearing retirement age. For example, in 2008 the Society

of Obstetricians and Gynaecologists of Canada (SOGC) partnered with the College of Family Physicians of Canada, the Canadian Association of Midwives, the Association of Women's Health, Obstetric and Neonatal Nurses, and the Society of Rural Physicians of Canada to produce a document, *A National Birthing Initiative for Canada* (Society of Obstetricians & Gynaecologists of Canada, 2008). This document, which emerged from an unusual partnership among front-line providers of maternity care, pointed to potential future shortages in health human resources (see also Chapter 1, section 8.4). As one example, although there were 1,650 obstetricians and gynaecologists in Canada, about 600 were planning to retire within the next five years, while others were reducing the number of deliveries they did. Similarly, an increasing proportion of family doctors reported that they did not provide any maternity or newborn care in their practice.

CIHI reported that family doctors said that the reasons why they were not delivering babies were related to concerns about their personal lives, confidence with their obstetrical skills, fee structures, and the perceived threat of malpractice suits. However, rural family physicians were more likely to provide obstetrical care than their urban counterparts; 27% reported delivering babies in 2000, compared with 12% in urban areas (Canadian Institute for Health Information, 2004b). Among the factors affecting the need for services were declining birth rates, older mothers, and an increase in multiple births. This in turn suggests the need to ensure that those involved with birth and delivery have greater expertise than would be the case if providers only included it as one component of a primary care practice.

Quality is discussed below, under the site of care.

Proponents of home births argue that women should have the choice as to where they can give birth. They argue that home births for low-risk women are safe and avoid unnecessary medical interventions that are common in hospital births. Giving birth at home in a familiar setting can provide women with more comfort and control.

Patient preferences also vary. One key debate is the extent to which pregnancy and childbirth should be seen as a medical problem, or a normal and natural event. Advocacy groups often object to the medicalization of childbirth. Others note that medicalizing a condition which could be alleviated can be positive (e.g., glasses can help deal with poor vision). Midwifery has often positioned itself as responding to "consumer demand". For example, the Ontario College of Midwifery describes their care as being "influenced by the natural childbirth movement principles that pregnancy and birth are normal, healthy, family events and that pregnant women themselves should be the primary decision makers about the health care they receive. Community midwives, together with the women they served, developed a model of care based on the principles of informed choice, continuity of care, choice of birth place, non-authoritarian relationship between woman and caregiver, time spent with women, and appropriate intervention" (College of Midwives of Ontario, 2011).

## ***2. Discuss the site of birth. Who would do the delivery? Do they need backup? What relationship should there be between midwives and family practitioners?***

Births can occur in hospitals, birthing centres, or at home.

The quality associated with planned home births is still a contested issue in maternity care. Indeed, much of the opposition to regulating midwifery in the early 1980s was based on beliefs that planned home births were unsafe for both the mother and the child, particularly if complications arose that could not be adequately addressed in the home setting. Since unpredicted emergency situations can arise even with low risk women, safe home birth usually

requires the ability to rapidly access the necessary interventions. Models of care appropriate for women living near a hospital would thus differ from those appropriate for more remote areas. The case of the baby born on the Toronto Island is a clear example; had the home birth occurred elsewhere in the city, the outcome might have been different. (Indeed, one rationale for regulating midwives was precisely to ensure that birth attendants were better trained, and would avoid such potentially hazardous situations.)

Assessing the safety of home births has been controversial. As noted, women seeking home births may differ systematically from women seeking hospital births. Unplanned home births that occur when a woman suddenly goes into labour are likely to differ from planned home births where the necessary supports have already been arranged. A number of studies have concluded that planned home births for women at low risk, cared for by qualified midwives, with access to medical backup, show similar outcomes to physician-assisted hospital births (Janssen et al., 2009; Johnson & Daviss, 2005; McLachlan & Forster, 2009). In addition, planned home births do have a lower rate of medical interventions (e.g. electronic fetal monitoring) and of adverse maternal outcomes (e.g. postpartum hemorrhage) than hospital births, although these home birth babies were slightly more likely to require a subsequent hospital admission, usually for jaundice. This finding raises some safety concerns for women in rural/remote areas, where timely access to hospital care could be problematic. However, in the absence of randomized controlled trials (which would be difficult to conduct), the controversy continues. In the interim, there have been a number of efforts to define low risk pregnancy. The College of Midwives of British Columbia has established eligibility requirements for home births (Janssen, et al., 2009). In Nova Scotia, each of the District Health Authorities that employ midwives have developed policies on home births.

A related question is the composition of the team. Births can occur at any time, and few individual providers are willing to be available 24 hours/day, 7 days/week. Attending a birth also usually requires at least one individual for back-up; midwives doing planned home births work in 2-person teams. As noted in Chapter 1, section 7.2 (*Canada Health Act*), the definition of insured services only requires payment for physicians and hospitals, although provinces are able to extend this definition to cover other providers if they wish to do so. However, any health providers who are classified as practitioners under the *CHA* must accept what the provincial/territorial fee schedule is willing to pay; extra billing will not be permitted. A related question is who will be in charge of the health team (which also relates to issues of medical liability in case of adverse events). Traditionally, physicians have been in charge of health care teams, although there are increasing cases where they are willing to work more collaboratively. Nonetheless, these issues will have to be clarified as models of care are developed.

A related issue is determining the best mix of obstetricians, family physicians, midwives, and other care providers to meet the need for maternity care. In turn, this has implications for training, costs, scopes of practice, and the delivery of health services, as well as which care models (and providers) will be publicly paid for.

One option receiving increased attention is to set up midwife run birthing centres. Quebec has done so successfully, and in 2012 Ontario announced its intention to set up two such centres in the province.

### ***3. Discuss professionalism, and the advantages and disadvantages of regulation.***

As noted in Chapter 1, section 6.4 (Professionalism), professionals are defined in terms of possessing specialized knowledge (attested to through certification procedures), providing

services to the public, where there is a risk to the public if the services are not done properly (Freidson, 2001). Because only the professionals are in a position to judge the quality of such services, professional regulation is expected to protect the public (see also Chapter 1, section 5.2.1, Regulation). However, it also lends legitimacy and credibility to the group that is designated as a profession, and may serve to enhance their autonomy, and their income.

Midwives thus face the dilemma of whether they wish to establish and enforce clear standards and entrance criteria, or to encourage a wider range of providers, including those who were trained through apprenticeships rather than formal educational programs. Individuals without formal training may also assist with birth and delivery. One tension was whether midwives also had to be nurses; in most jurisdictions, midwives were recognized as a separate profession rather than as a nursing subspecialty. There is also a potential philosophical conflict between a medicalized view, and one focused on more “natural” ways of supporting women throughout pregnancy and childbirth. Professional midwifery groups have decided that becoming a regulated profession, despite its potential limiting effects, is worthwhile.

With regard to midwifery, at the time of writing, there were multiple education streams to become a midwife in Canada. Direct entry baccalaureate programs in midwifery were offered in Ontario by McMaster, Laurentian and Ryerson Universities, in British Columbia at the University of British Columbia, in Quebec at the Université de Québec, Trois-Rivières and for aboriginal midwifery in Manitoba at the University College of the North in Manitoba. Ryerson University in Toronto offered a 9-month Bridging Program for internationally educated midwives (IEM) who have practiced within the last 5 years and are fluent in English. Other provinces periodically provide Prior Learning and Experience Assessment (PLEA) programs for IEMs seeking to practice. Additional Aboriginal training programs were provided by the Nunavut Arctic College Midwifery Education Program, the Nunavik Community Midwifery Education Program and the Six Nations Aboriginal Midwifery Training Program.

#### ***4. Discuss the role of interest groups in making policy, including the women’s movement and the consumer movement.***

Interests are often major influences on policy making (see Chapter 1, section 4). Initially, midwifery attracted considerable support from women’s health advocacy groups, and also had some ties to the public health community. Some might have described these supporters as the “granola” contingent, particularly given their emphasis on natural childbirth and their positioning of midwifery as being an alternative to traditional medical care, rather than as working in partnership with it. Medical associations and regulatory Colleges, along with obstetrician and gynaecology organizations, were initially opposed to the implementation of midwifery. However, in the last ten years, as midwifery has become a regulated profession in many jurisdictions, and as the climate of health care has changed, physicians generally have become more supportive and are increasingly seeking out collaborative practice models. Midwifery has also attracted support from professional nursing associations, although it has also found detractors among nursing unions and sometimes, nursing colleges.

One example is Ontario, which leveraged support from “a small group of midwives, consumers, health care providers and other supporters of midwifery” who had formed a consumer-based lobby group that they named the Midwifery Task Force of Ontario (MTF-O). Their lobbying has been seen as a major influence on midwifery gaining professional regulation and being integrated into the healthcare system (College of Midwives of Ontario, 2011).



**See also in Chapter 1:**

- 4 Interests
- 5.2.1 Regulation
- 6.2 Payment Mechanisms and Incentives
- 6.4 Professionalism
- 7.2 *Canada Health Act*
- 7.3 Regulating Health Professionals
- 8.4 Health Human Resources

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**The following websites may also be helpful:**

Canadian Institute for Health Information (CIHI). Giving Birth in Canada. This series of reports includes an analysis of Providers of Maternity and Infant Care; a Regional Profile of selected indicators; and The Costs, as well as updated indicators. <https://secure.cihi.ca/estore/productSeries.htm?pc=PCC226>.

Canadian Midwifery Regulators Consortium. <http://cmrc-ccosf.ca/node/18>

## **Chapter 10: Teaching Notes**

### **The Demanding Supply: Licensing International Doctors and Nurses in Ontario**

*Mohamad Alameddine, Charles Battershill, Andrea Baumann, Maureen Boon, Karen Born, Andrea Cortinois, Rinku Dhaliwal, Adam M. Dukelow, David Hoff, Carolina Jimenez, Nibal Lubbad, Maria Mathews, Glen Randall, Melissa Rausch, and Raisa B. Deber*

#### **Outcome**

In 2010, the College of Physicians and Surgeons of Ontario (CPSO) had issued 3,708 certificates of registration – the highest in their history. It was the 13<sup>th</sup> consecutive year that the number had increased. The number of physicians in active practice had increased 20% since 2000. Over 20 years, the International Medical Graduates (IMG) share had risen from 16% to 41% of the total number issued; in 2010, they received 1,522 certificates. For the 7<sup>th</sup> consecutive year, more certificates were issued to IMGs than to Ontario graduates. Recognizing that some of those certificates were associated with postgraduate residency training, there were still 1,617 new practice certificates issued, of which 636 were issued to IMGs. (College of Physicians and Surgeons of Ontario, 2011)

The increase for nurses was less dramatic. In 2006, there had been 325,299 nurses in the Canadian nursing workforce of which 21,395 were internationally educated nurses (IENs). More than half of the foreign-trained nurses in Canada were practicing in hospitals in Ontario, primarily in central Toronto and surrounding cities. In general, IENs were almost equally likely to leave the workforce as to enter it; between 1997 and 2006, 6,832 IENs entered the Ontario workforce and 6,024 left. Some of the barriers foreign-trained nurses faced included: insufficient practical information about jobs before coming to Canada, long absences from practicing nursing, the need to take upgrading courses to meet new entry-to-practice requirements (four-year baccalaureate degree) and poor communication skills (Blythe & Baumann, 2008; Blythe, et al., 2006). Among the solutions suggested were: group and individual counseling on educational needs; upgrading in stages; development of a mandatory adaptation program; and the establishment of international nursing education standards.

Note that Canada's Agreement on Internal Trade required each of the professions to develop a system to ensure that professions practicing in one province have access to other provinces. Although most professions have largely complied, this is less true for physicians; at the time of writing, for example, it was still difficult for an IMG practicing in Newfoundland to move to Ontario.

#### **Possible Points for Discussion:**

***1. Discuss the various levers government has to control the numbers and distribution of nurses and physicians in the health care system? How is this affected by the distribution of powers between the federal and provincial/territorial governments?***

Note that the federal government controls immigration, while the provinces pay for the costs of insured services, which are often delivered by doctors and nurses. Professional

registration is determined by self-regulating colleges. In terms of controlling the distribution of providers, as noted in the case, physicians often decide where they wish to practice, while nurses are usually hired by independent provider organizations, depending on the funds that these organizations have available.

The possible levers to control the supply of providers include:

- a) Enrollment in training programs, which may also include size of the entering class, admission criteria for entering students, and/or sources and amount of funding for training programs;
- b) Assessment protocols for international graduates. This is related to both immigration policy, and the assessment process for such graduates (including the number of positions available should such training be required);
- c) Licensing Requirements, including rules about the number of post graduate training positions available, whether these are open to international graduates, the duration of training, and/or the number of licenses granted by the regulatory Colleges (overall or specifically for IMGs, IENs, etc.);
- d) Controls over physician billing numbers, possibly including moves to other forms of reimbursement;
- e) Controls over geographic distribution (e.g., licenses tied to where the person will practice); and/or
- f) Controls over distribution by specialty.

One question is how the problem should be defined. For example, what is a “full time equivalent” physician? Physicians currently work fewer hours than they did in the past, which may mean that more providers (albeit, if interdisciplinary care models are employed, not necessarily more physicians) would be needed to provide a similar level of service.

There are similar levers available to affect the supply of nurses, including enrollment (both opening new schools and/or expanding current programs), and increasing the number of IENs. Other possible levers relate to improved recruitment and retention, length of training programs, and focusing on labour substitution. As noted, differences in how various types of health human resources (HHR) are paid can have a significant impact on which policy levers are likely to be effective. The choice of what policy avenues to pursue also depends on such factors as political and economic climates, with the strength of the interest groups involved often playing a major role.

***2. How would your preferred policy options differ if the issue was framed in terms of: Costs? Efficiency? Access? Quality of care? Equity or rights of: potential providers; Canadian residents wishing to become HHR; countries from which these providers are coming? Immigration policy?***

As noted in Chapter 1, section 3.4 (Framing), how a question is framed may affect how it is dealt with. The “need” for HHR can be framed in a number of ways, including: health care system costs, health care system efficiency, equity or rights of potential professionals, and/or public access to services. For example, from the view of cost, more HHR can be seen as an added cost, particularly if government is paying the bills, but care cannot be provided without HHR. Perhaps the most important policy issue this case raises is the delicate balance between competing goals. As noted in Chapter 1, section 3.3 (Policy Goals), Stone suggests four key policy goals: efficiency, equity, security, and liberty. On their own, they are all desirable; the policy dilemma is how to balance them and handle the inevitable tradeoffs (Stone, 2002).

Political conflicts often affect which goals are emphasized. These objectives are also prone to competing interpretations. How many local/foreign medical graduates do we “need”? Who would benefit from them? There is often no correct answer for these questions; the issue of whose goals should take priority is often political.

*Efficiency* is defined as “getting the most out of a given input” or “achieving an objective at the lowest cost” (see Chapter 1, section 3.3.4). At the societal level, efficiency as a policy goal may help to guide how society chooses to spend its money or allocate its resources. From a narrow efficiency viewpoint, one might even argue that the best approach is to close all Canadian training programs and rely solely on IMGs, as well as deskilling and relying on lower-paid providers. Clearly, such a policy would present other problems.

*Equity* as a policy lens forces us to consider why it is proper to categorize cases as alike or different. Can we justify putting IMGs and foreign medical schools in a different category from Canadian graduates and medical schools? If so, why? One justification for restricting IMGs could be the alleged lower or unknown quality of their medical education, which would frame the policy in terms of protecting Canadians. Yet many IMGs are as or more competent than Canadian-trained providers. Using Stone’s chocolate cake example (see Chapter 1, section 3.3.3, Equity), one could look at various dimensions involved in making an equitable allocation decision. She specifies four, which she terms recipients, distribution, items, and process.

Viewing equity in terms of the potential *recipients*, one might ask who should count as a member of the class (here, of those being allowed to practice their profession). Should IMGs be counted among the group entitled to access? Clearly, the route to becoming a registered doctor is also severely restricted for Canadian students due to limited access to medical education. One could accordingly ask to whom are we trying to be fair. Responses might include various combinations of IMGs, Canadian medical graduates (many of whom could have been born outside of Canada), those who were unable to be admitted to Canadian medical schools, patients and potential patients, and taxpayers.

One might also ask how one would distribute the scarce resource. A number of approaches could be employed. *Rank-based distribution* contends that there are relevant internal divisions for distributing something, which can be linked to concepts of horizontal and vertical equity (i.e., treat same rank equally and different ranks unequally). Some argue that Canadian graduates should be ranked higher than IMGs when postgraduate training positions are assigned; in fact, this has been the practice for many jurisdictions. Changes in the definition of “accredited” medical schools is a good example of what could be termed as “floating ranking”, since other schools in the Commonwealth were originally considered equal to Canadian and American schools in terms of licensure, but no longer are. Another option is *distribution based on social cleavages* (i.e., gender, ethnic groups, income); this could include giving preference to groups who had suffered historical disadvantages, but one might also argue that the individuals receiving such preferences were not the ones who had been discriminated against. Setting aside a fixed number of spots for IMGs (24 for some of this period) could be seen as a restriction (if IMGs would have received more spots if judged on their own merits) or as a benefit (e.g., if the prior number was effectively 0 because IMGs had been informally excluded from these positions).

The next dimension in Stone’s typology is the *items* being distributed and how to define the “boundaries” of what is to be distributed. In Stone’s terms, are we just talking about the cake, or should the cake be considered in the context of a larger meal? If somehow I had received a lesser share of a previous meal attended by the members of the class, could I argue that I should

receive preference with respect to the cake? For this case, one might ask what value should be assigned to a medical degree or a nursing degree.

The final dimension in Stone's classification is the *process* used. As noted in Chapter 1, section 3.6 (Ethical Frameworks), process is important because people may be more willing to accept unequal results if the process is considered fair. Process may be particularly important when the items being distributed cannot be divided, meaning that if one person gets the item, others cannot. Processes used to distribute scarce resources could include competition, lottery, and/or election. In terms of process, one might then ask whether it is fair to treat foreign-trained doctors and nurses differently from graduates of Canadian training programs (who, as noted previously, could have been born outside of Canada but educated in Canada).

As was noted in Chapter 1 (section 3.3, Policy Goals), policy must often deal with balancing such goals as efficiency and equity. From the viewpoint of efficiency, one would wish to ensure that goals are realized at minimum cost. From the viewpoint of equity, one might want to ensure that "likes" are treated alike. From the viewpoint of efficiency, one might be happy to import providers from the cheapest source. From the viewpoint of security, one would want to ensure that all providers are properly trained and are located where they are needed. From the viewpoint of liberty, one might argue that people should be free to live and work where they want. How can government set a policy which allows it to service the health needs of its population at the most reasonable cost as well as achieving its goal of being fair to its citizens and residents? This leads to several other questions, including what the population needs, what a reasonable cost would be, how those needs could be met most efficiently, who gets the benefits and bears the burdens of a policy, how we should measure the values and costs of a policy, and what fairness really means.

Yet another complexity arises when policy issues are framed in terms of *rights*. For example, should an IMG have the same right to practice his/her profession as someone trained in Canada? Should any qualified Canadians wishing to enroll in medical school be able to do so, or should the numbers be restricted to the number "needed"?

Obviously, there are many different rights here, associated with many different groups. Taken individually, each group's assertion has merit and seems reasonable. Taken in the context of society, however, not all of these groups can possibly get what they feel they deserve. Where resources are limited, someone will lose. The problem of framing policy questions in terms of rights has been described by Glendon as "rights talk". As he writes: "(Rights talk) is set apart from rights discourse ... by its starkness and simplicity, its prodigality in bestowing the rights label, its legalistic character, its exaggerated absoluteness, its hyper individualism, its insularity, and its silence with respect to personal, civic and collective responsibilities....By indulging in excessively simple forms of rights talk ... we make it difficult for persons and groups with conflicting interests and views to build coalitions and achieve compromise" (Glendon, 1991).

There is a major difference between equality of opportunity and equality of results, sometimes referred to as procedural and substantive equality. For example, "equality before the law" means that everyone is subject to the same law. However, as shown by the failed challenge under the Canadian *Charter of Rights and Freedoms* referred to in the case, it does not mean that the law itself treats people equitably. Other potential rights issues could relate to the ability to provide culturally sensitive care to new Canadians, as well as whether poorer countries are being deprived of needed HHR if their skilled professionals move to richer countries, particularly when the sending countries have paid to train them (see also Chapter 1, section 5.5, Globalization) (World Health Organization, 2011).

Resolving the conflict between a human rights frame and a cost control frame when dealing with IMGs was simplified when policy makers believed that there was a shortage of physicians and nurses; this meant that foreign-trained professionals could be accommodated without affecting Canadian-trained HHR. Since it is less clear that the shortage still exists, or that the supply of physicians and nurses should continue to grow, one can predict that the way this issue is framed in Canada is likely to change.

### ***3. What are the differences between dealing with the issues of human resource supply of medical personnel and of nursing personnel?***

One important difference between HHR planning for physicians and nurses relates to the connection between licensure and employment. As noted, being licensed as a nurse does not guarantee employment. If the relevant regulatory college decides to accept the credentials of a foreign-trained nurse, there is no automatic requirement to give her/him a job and pay her/his salary. In contrast, in most Canadian jurisdictions, being licensed as a physician involves automatically being granted a billing number. The medical education system largely assumes that there should be one job for every person who has been trained, which recognizes the value of these highly skilled HHR and the reluctance to waste them. However, that system means that education, licensing and employment are inextricably linked in the medical profession in a way that is quite different from other professions, including nursing. This has implications for HHR planning. IMGs upset the delicate balance of physician training and employment in a way that is less true in other professions (including nursing).

The methods of payment are thus critical. Those paid on the basis of fee for service (FFS) have greater ability to generate income than do those who must be hired into salaried positions. There are also significant differences in where the benefits/risks of over/undersupply fall. In a salaried model, supply and demand would suggest that periods of shortage give the advantage to workers, who can then bargain for better wages and benefits, improved working conditions, etc. Conversely, periods of surplus give the advantage to employers. In practice, this risk can harm retention; nurses may not remain on hold until they are “needed” again, and people may be more reluctant to train for professions that cannot offer job security. One study of Ontario found that when hospitals reacted to budget constraints by laying off nurses, the nurses were more likely to leave the profession than to move to the community sector (Alameddine et al., 2009; Alameddine et al., 2006). This loss of skilled resources is expensive, and often foolish. This also clarifies why existing professionals may not wish to drive down the prices and need for their services by allowing more people to become registered.

Physicians have a significant degree of control over the demand for their services since they have the ability to order medical care. Nurses’ control over demand is much more limited. More importantly, since the majority of Ontario physicians are paid on a FFS basis there is a built in financial incentive to use their control to drive demand. Such an incentive does not exist for salaried nurses (or salaried physicians). The class may wish to discuss how the shift in how physicians are paid (from primarily FFS to blended models incorporating salary and capitation components) is likely to affect the willingness of different groups to license IMGs.

### ***4. What interest groups are involved here? How could the characteristics of the various groups involved influence the outcome of this dispute?***

As noted in Chapter 1, section 4 (Interests), the strengths of the various interest groups involved in this case have had a major impact on how policies have evolved. The medical

profession as a whole is represented by several extremely powerful and effective interest groups. IMGs and under serviced communities (such as many in Northern Ontario) are less well organized. Indeed, in 1976, health economist Robert Evans had correctly predicted that the IMGs' lack of political strength would make them most expendable in times of system rationalization (Evans, 1976).

A wide array of groups might have been involved. One category of groups were organizationally part of government, at various levels (including federal, provincial/territorial, and local); they came from departments associated with different policy issues, including immigration, education, and health, as well as arm's length bodies set up to assess IMGs (e.g., IMGO) and, to the extent legal issues arose, the courts. Other members of the policy community included organizations associated with training HHR (e.g., Faculties of Medicine), professional registration (e.g., colleges of nurses, physicians, etc.), professional organizations (e.g., Canadian College of Family Physicians, Royal College of Physicians and Surgeons, and provincial medical and nurses associations, associations of interns and residents, etc.), employers of HHR (e.g., hospitals and hospital associations), and those associated with internationally trained HHR (e.g., Association of International Physicians and Surgeons of Ontario). Less organized, but clearly interested, were the foreign medical and nursing graduates themselves, and the various immigrant and multicultural associations, who might also have a desire to ensure that they could be treated by HHR who understood their culture and language. Other potential interests, usually even less organized, were patients and potential patients, under-served communities, and taxpayers.

As noted in Chapter 1, section 4.3 (Scope of Conflict), the participants, definition of the issue, and outcomes also varied depending on how the issue was defined, and where (and by whom) it was discussed. Outcomes could vary, depending on which lens decision makers were looking through (e.g., ensuring that quality was maintained among those being licensed, HHR planning, legal rights under the Charter, and/or citizenship and immigration policies).

### ***5. What are the advantages and disadvantages of self-regulation of professions in terms of public interest, as well as financial and political costs?***

As noted in Chapter 1, section 6.4 (Professionalism), one element of a profession is that only members of that profession are in a position to assess what constitutes good/bad practice. Accordingly, government has delegated its authority to professions to regulate themselves, in the expectation that this will be done in the public interest. The professional Colleges (e.g., of physicians, nurses, etc.) have been given the power to define standards of practice within their respective scopes of practice and the power to enforce those standards. Each individual professional is expected to act as the agent of his/her patient in advising and procuring care. This model of self-regulation was also attractive to government, which was thereby insulated from a range of potentially politically sensitive policy decisions. The down side of self-regulation is that there is no guarantee that the profession will always use the authority that government has delegated to it in the public interest rather than in the interest of promoting and protecting the profession itself. For example, if professional organizations decree that their current members are superior in quality to the foreign-trained, this can also help reduce competition and maintain better wages and working conditions for the existing members. The literature accordingly varies in how professional self-regulation is viewed.

### ***6. What are the strengths and weaknesses of present forecasting models used to predict supply***



**and demand?**

Chapter 1, section 8.4.1 (Projecting Supply and Demand) provides some information on how forecasting can be done. Note that a series of physician manpower studies in the 1970s undertaken by such groups as Health and Welfare Canada, the National Committee on Physician Manpower, the Council of Health and the Council of Ontario Faculties of Medicine all warned against hasty cutbacks by government. They argued that poor distribution of physicians by geography and specialty could be solved by continuing to have modest increases in supply, thereby ensuring that some of these physicians would go to underserved areas. This is sometimes called the “over-flowing pot” market solution; it argues that, by having a larger pool of physicians, you will increase the possibility that some will move to help meet the demand in under serviced areas. This model does not address the issue of areas that may become overserved as a result; neither does it ensure that providers will actually go where they are needed. (One reason why underserved areas have problems attracting physicians is the on-call schedule; if there is only enough population to support two physicians, then each must be on call half the time, which leaves little time for a family life. Some have estimated that practices would need to include, at minimum, 5 providers to enable them to have a reasonable on-call schedule, which is difficult to implement if there are not enough potential patients to support that many providers.)

One review of physician manpower planning argued that there were two essential components, establishing the current and future supply; and calculating requirements/demand (Lomas et al., 1985). It is important to note that the consequences of different errors in forecasting will vary. Concluding that there is a surplus may require unpopular reduction in provider numbers; concluding that there is a shortage may require spending more money and training more people.

Discussing physician supply planning may lead to questions about how the shift in thinking from a surplus to a shortage occurred over such a short period of time. Chan analyzed this issue, and concluded that the following factors contributed to the perceived change in supply (in order of contribution amount): 1) increased length of postgraduate training (the minimum length of post graduate training for family physicians increased from one to two years in 1991); 2) decreased intake of IMGs; 3) increased number of physician retirements; 4) decreased Canadian medical school enrollment; and 5) loss of physicians to the United States (Chan, 2002).

When considering the perceived shortage, one must also consider the change in specialty distribution of physicians. Following Barer and Stoddart’s report (Barer & Stoddart, 1991) which was also summarized in a series of a series of articles (Barer & Stoddart, 1992a, 1992b, 1992c, 1992d, 1992e; Stoddart & Barer, 1992a, 1992b, 1992c, 1992d, 1992e, 1992f), various policies were introduced to increase the specialist to family physician ratio. As a result, during the 1990s the decrease in physician supply was mostly seen in terms of family physicians. Perhaps this is the most “visible” portion of the physician supply to the general public, particularly in smaller communities; this may have led to an overestimated public perception of the shortage.

In addition, workload distribution must be considered. Changing who provides care (including increased use of multidisciplinary teams), where it is provided and how it is funded would also alter the “need” for physicians or nurses.

**See also in Chapter 1:**

- 2.2.1 Federalism in Canada: *The Constitution Act, 1867*
- 2.2.2 Charter of Rights and Freedoms

- 3.3 Policy Goals
  - 3.3.3 Equity
  - 3.3.4 Efficiency
- 3.4 Framing
- 3.6 Ethical Frameworks
- 4 Interests
  - 4.3 Scope of Conflict
- 5.5 Globalization
- 5.9 Insurance, Elasticity and Moral Hazard
- 6.1 Dimensions of Health Systems
  - 6.1.1 Public and Private
  - 6.1.2 Financing and Delivery
- 6.2 Payment Mechanisms and Incentives
- 6.4 Professionalism
- 7.2 *Canada Health Act*
- 7.3 Regulating Health Professionals
- 8.4.1 Projecting Supply and Demand

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<http://www.who.int/hrh/resources/guide/en/index.html>.

**The following websites may also be helpful:**

- Association of Faculties of Medicine of Canada (AFMC) <http://www.afmc.ca/about-e.php>
- Canadian Association of Schools of Nursing <http://www.casn.ca/en/>
- Canadian Information Centre for International Credentials  
<http://www.cicic.ca/en/professions.aspx?sortcode=2.19.21&prof=3112>
- Canadian Medical Association has information on Physicians per 100,000 population  
[http://www.cma.ca/multimedia/CMA/Content/Images/Inside\\_cma/Statistics/12-Phys\\_per\\_pop.pdf](http://www.cma.ca/multimedia/CMA/Content/Images/Inside_cma/Statistics/12-Phys_per_pop.pdf)
- CARMS <http://www.carms.ca/en/carms-overview>
- Centre for the Evaluation of Health Professionals Educated Abroad (formerly IMG-Ontario)  
<http://www.cehpea.ca/>
- Citizen and Immigration Canada <http://www.cic.gc.ca/english/index.asp>
- Health Canada, Health Human Resource Strategy, includes links to Pan Canadian Health Human Resource Strategy and page about Internationally Educated Health Care Professionals.  
<http://www.hc-sc.gc.ca/hcs-sss/hhr-rhs/strateg/index-eng.php>
- HealthForceOntario <http://www.healthforceontario.ca/>
- Nursing Health Services Research Unit <http://nhsru.com/> and  
<http://nhsru.com/category/publications/international-nursing>
- Office of the Fairness Commissioner <http://www.fairnesscommissioner.ca/en/index.php>
- Ontario Hospital Association. Internationally Educated Nurses. [www.oha.com/en](http://www.oha.com/en)
- Ontario Ministry of Health and Long-Term Care: International Medical Graduates  
[http://www.health.gov.on.ca/english/providers/project/img/img\\_mn.html](http://www.health.gov.on.ca/english/providers/project/img/img_mn.html)



## Chapter 11: Teaching Notes

### Primary Health Care in Ontario: Inching towards Reform

*Monica Aggarwal, Munaza Chaudhry, Stephanie Gan, Nada Victoria Ghandour, William Kou, Leslie MacMillan, Catherine L. Mah, Meghan McMahon, Lucinda Montizambert, Allie Peckham, David Rudoler, Rena Singer-Gordon, Debra Zelisko and Raisa B. Deber*

#### Outcome

As noted in the case, Ontario has developed and implemented an array of primary care models and compensation schemes, many of which represent reiterations of or subtle variations on past models. The resulting “alphabet soup” includes Family Health Organizations (FHO), Family Health Networks (FHN), Family Health Groups (FHG), Family Health Teams (FHT), Nurse Practitioner Led Clinics, Community Health Centres (CHC), and other specialized models (e.g. Group Health Centre in Sault Ste. Marie). They vary in terms of the funding model used (various blends of capitation, FFS, and global budgets), whether patients must be rostered, the roles and compositions of provider teams, governance mechanisms and comprehensiveness of services (e.g., the extent to which they also incorporate prevention, chronic disease management and/or addressing the social determinants of health).

Some (but not all) included provision for financing interdisciplinary teams. There are a number of ways to categorize these models. The Ontario Medical Association (OMA) has focused on the models that roster patients to particular providers, and distinguished between those that use blended capitation models, including Family Health Networks (FHNs, established in 2002), and Family Health Organizations (FHOs, from 2006); those that use enhanced FFS, including Family Health Groups (FHGs, from 2003), and Comprehensive Care Models (CCMs, from 2005); and other patient enrolment models. As of November 2011, the OMA had estimated that about 2/3 of family physicians in Ontario were in one of these reformed models; of those, over half were in blended capitation models (49.4% in FHOs and 4.2% in FHNs), about 41% in enhanced FFS models (37.3% in FHGs and 3.9% in CCMs) and the remaining 5.1% in other patient enrolment models (Kralj & Kantarevic, 2013). Traditional PHC models had not disappeared, but they were far less common than had been the case. That same report showed that about 10 million of Ontario’s 13 million population were now rostered to a family physician. One mechanism used to encourage physicians to join was to make the payment models generous, including significant bonuses for particular activities, and to allow physicians to choose from among a wide variety of options.

One result was that the number of patients without a regular primary care provider dropped; over 2 million patients who had not had a family doctor were enrolled in a primary care model. Another result, however, was that the cost of physician services in Ontario escalated. The precise figures can be disputed, with the Ontario Auditor General giving a high estimate (Office of the Auditor General of Ontario, 2011) and the OMA a lower one (Kralj & Kantarevic, 2013). According to the Canadian Institute for Health Information (CIHI), there has been a steady increase in physician costs over time (Canadian Institute for Health Information, 2013). Physician expenditures grew at an annual rate of 6.8% per year from 1998 to 2008, with over half of this growth (3.6% per year) attributable to increases in physician fee schedules (Canadian

Institute for Health Information, 2011). Some of this was driven by an increase in the number of providers, but much was attributed to the fact that physicians were receiving higher payments under the new payment approaches. The effectiveness of these new models has been mixed (Glazier et al., 2009). In 2012, the Ontario government was seeking to cap physician payments and was involved in heated disputes with the OMA about how to do so. Although a settlement was reached, the underlying issues remain. (One complicating factor, not often acknowledged in the debate, is that changes in how care is delivered have led to changes in how it is categorized. For example, much of Ontario's seeming increase in physician expenditures resulted from moving care from hospitals to independent health facilities, which has meant moving those costs from the hospital to the physician budget line (Deber & Allin, in press).)

### **Possible Points for Discussion:**

***1. What do you think have been the key objectives of primary care reform? Why do you think the Ontario government has implemented so many different types of primary care models? Do these models represent innovations or variations on a theme?***

As noted in the case, one key question is what is meant by primary care reform. Some stress it as a transition from primary care (PC) to primary health care (PHC) (Aggarwal, 2009). Some reforms attempt to improve PHC for its own sake, while others anticipate also affecting other parts of the system. Impacts may relate to changes in structures, process and/or outcomes. Depending on who defines (and assesses) success, analysts may emphasize benefits to payers, providers, patients, and/or the system as a whole.

A series of national reports have emphasized PC/PHC. For example: Health Canada included some primary care objectives as part of the \$800 million Primary Health Care Transition Fund, which gave federal money to the provinces for primary care reform initiatives over a six year period (Health Canada, 2007). These included: to increase the proportion of the population with access to primary health care organizations which are accountable for the provision of comprehensive services to a defined population; to increase the emphasis on health promotion, disease and injury prevention, and chronic disease management; to expand 24/7 access to essential services; to establish multi-disciplinary teams so that the most appropriate care is provided by the most appropriate provider; and to facilitate coordination with other health services (such as specialists and hospitals).

The Romanow Commission also viewed primary care reform as a move from an emphasis on PC to PHC (Commission on the Future of Health Care in Canada, 2002). To achieve this transition the Commission had set out the following priorities: continuity and co-ordination of care: reducing system fragmentation for patients; early detection and action, including a focus on risk factors for chronic disease; better information on needs and outcomes, including the implementation of electronic health records; and new and stronger incentives, including financial incentives, better funding schemes for primary care practices, recognition of work-life conditions for primary care staff and a focus on incentivizing improvements in quality of care.

In their recommendations on primary care reform, the Kirby Senate Committee supported the continued federal role in promoting the following objectives: a continued emphasis on the implementation of multidisciplinary primary health care teams that: are working to provide a broad range of services, 24 hours a day, 7 days a week; strive to ensure that services are delivered by the most appropriately qualified health care professional; utilise to the fullest the



skills and competencies of a diversity of health care professionals; adopt alternative methods of funding to fee-for-service, such as capitation, either exclusively or as part of blended funding formulae; seek to integrate health promotion and illness prevention strategies in their day-to-day work; and progressively assume a greater degree of responsibility for all the health and wellness needs of the population they serve (Standing Senate Committee on Social Affairs Science and Technology, 2002).

One major impetus of these reforms was the desire to move family physicians out of FFS compensation into what were perceived as more efficient and effective compensation schemes (Hutchison et al., 2001). The aim was to provide physicians with a variety of carrots to entice them to make the switch out of FFS (Barnes & Macleod, 2008). These new models provided the government with a greater ability to encourage physicians to incorporate particular activities into their day-to-day business operations (e.g., 24/7 access, incentives for chronic disease management, multidisciplinary care, etc.). As noted in Appendix B of the case, in the 1970s-90s, such primary care models as Health Service Organizations and Primary Care Networks had not been popular enough choices to move a majority of Ontario physicians out of FFS (Abelson & Birch, 1993). FHGs, an enhanced FFS model introduced in 2003, may have acted as a bridge to such other payment schemes as blended capitation. Although discussion of the variations within each of these models is beyond the scope of this case study, the fact that so many models are in use suggests unwillingness by the provincial government to force physicians into any particular model. Instead, it has allowed them to choose their preferred model. Some note that many of the newer models featured a heavier emphasis on FFS, and more money for physicians, and suggest this is due in part to the power of the medical profession in Ontario.

## ***2. What explains policy stasis and policy change in the primary care reform context?***

One theory that has been used to explain the slow pace of change is historical institutionalism and path dependency (see Chapter 1, section 2.3, Historical Institutionalism, Path Dependency, and Policy Legacies). That theory postulates that governments' policy choices and priorities are often shaped and constrained by past policy decisions. Among the key decisions influencing how health care is organized and delivered in Canada is the constitutional provision assigning health care to the provinces/territories (see Chapter 1, section 2.2.1, Federalism in Canada), and the decision to set up public insurance programs incrementally, initially covering hospital care, followed by physician services (see Chapter 1, section 7.1, Financing Health Care in Canada). In turn, this led to the provisions in the *Canada Health Act* (see Chapter 1, section 7.2, *Canada Health Act*) that define comprehensiveness in terms of medically necessary services, but only if delivered in hospitals or by physicians. Historically, physicians have been paid on a FFS basis (see Chapter 1, section 6.2, Payment Mechanisms and Incentives), with the fee schedules negotiated between the provincial/territorial ministry of health, and the association representing the province's physicians. This historical legacy has meant that adding non-physician members to health teams could be seen as an "add-on" cost not required by legislation.

Another policy legacy, common to most health care systems in developed countries, is the central role that physicians and the medical profession have played in health care, including primary care, and the longstanding dominance of solo-based, FFS practice. Another key factor is the need for the expertise and clinical judgment of physicians in delivering high quality care, and the strong support physicians usually receive from the public. As professionals, physicians have tended to be resistant to potential challenges to their autonomy (see Chapter 1, section 6.4,

Professionalism). Depending upon the jurisdiction, there may or may not be an acceptance of multidisciplinary teams of health providers, particularly where one profession (usually physicians) had been seen as being in charge. When push comes to shove, provincial governments have tended to be unwilling to battle physicians (Aggarwal, 2009), although, faced with deficits, the Ontario government was doing so at the time of writing (2012).

**3. What do you think are the most important elements of primary care reform and why? Discuss the implications of: different payment mechanisms; use of different health care providers; health promotion, illness prevention and chronic disease management; and integration with other parts of the health care system.**

*Payment Mechanisms:* One key aspect of primary care reform has been the implementation of a variety of physician compensation mechanisms. As noted in Appendix A of the case, in Canada, family physicians are typically compensated through one of six compensation schemes: 1) FFS, 2) enhanced FFS; 3) blended capitation, 4) blended salary, 5) salary, and/or 6) blended complement. All have different incentives and disincentives.

Robinson summarized the key disincentives associated with three of the main funding models as follows: “Fee-for-service rewards the provision of inappropriate services, the fraudulent upcoding of visits and procedures, and the churning of “ping-pong” referrals among specialists. Capitation rewards the denial of inappropriate services, the dumping of the chronically ill, and a narrow scope of practice that refers out every time-consuming patient. Salary undermines productivity, condones on the job leisure, and fosters a bureaucratic mentality in which every procedure is someone else’s problem” (Robinson, 2001).

There is a vast body of literature from within Canada and abroad that examines the impacts of alternative payment mechanisms on provider behaviour, and on such health care goals as access, cost, patient and physician satisfaction. The impacts also link to whether the quality problems are related to overuse, underuse, or misuse (Institute of Medicine, 2001). *FFS* tends to reward production/productivity, and gives providers greater ability to meet income targets. This is appropriate if one wishes greater volume, and problematic if one fears incenting inappropriate utilization. It may also encourage multiple short visits, but be problematic if one wishes to encourage collaborative care. *Capitation* focuses attention on the needs of the patient population and may encourage longer, more comprehensive visits and team-based approaches; it also may encourage such innovations as telephone monitoring. Keeping patients on a roster may incent activities to increase patient satisfaction. However, there may be an incentive to avoid high cost patients and under serve and/or, depending on the payment model, to “off load” to specialists. This model also produces a more predictable income for health providers and more predictable expenditures for payers. *Salary* divorces the incentives for individual providers from those for the organization. A salaried provider may be encouraged to spend more time with patients, but also to be less productive. From a system viewpoint, costs and incomes are more predictable, and flexible use of providers and teams can be encouraged.

In summary, each funding model comes with a number of incentives and disincentives. There is no ideal model; rather, the advantages and disadvantages must be weighted in the light of the policy goals and objectives. Clearly, some models perform better on cost containment (e.g., salary), others on productivity (e.g., FFS or blended models), and others still on team-based care. It is also important to note that sometimes the decision around funding model must reflect the characteristics of a population being served. For example, neither FFS nor capitation may be appropriate for providers servicing small populations (particularly but not exclusively in rural

and remote areas), since the resulting revenues would usually be insufficient to sustain a practice. (Economists might view this in terms of the “option value” of having providers available in case they are needed, recognizing that much of the time, they would not be required.) There is also a trend, particularly in the US and UK, towards attempting to *pay for performance*. In practice, such models may indeed improve quality, but often tend to resemble modified FFS (Hurley et al., 2011; Peckham & Wallace, 2011; Wilensky, 2011).

Recommendations for PHC reform have often included the implementation of *health care teams*. The class may wish to discuss the advantages and disadvantages of solo practice vs. multidisciplinary teams, including likely impact on use of skills, distribution of workload, continuing education, availability of specialized expertise and equipment, roster size, and satisfaction of patients and providers. They may also wish to discuss which of these providers should be on PHC teams and under what circumstances including: GP/FPs, nurses, nurse practitioners, nursing educators, public health nurses, counsellors, midwives, dietitians, pharmacists, chiropractors, physiotherapists, occupational therapists, social workers, mental health workers, specialists, psychologists, specialized therapists, team liaison persons, clinic managers and/or home care helpers. They may also wish to discuss the potential role of governance structures (e.g., the differences between a physician-led model, and one using community governance, such as the Community Health Centre model).

The emphasis on *health promotion, illness prevention and chronic disease management* is another potential source of difference between models. To some extent, this may involve recognition of the social determinants of health, although is not precisely a population health approach, since it still focuses on individual patients rather than on a broader community. Primary care providers are typically patient’s first point of access to the health care system and are the providers they see most often to obtain care for chronic diseases (Macinko et al., 2003). Recognizing that the determinants of health go well beyond health care (see also Chapter 3, Making Canadians Healthier), primary care does, in theory, adopt a patient-centred rather than disease-specific approach to care, potentially being more able to manage patients who have multiple morbidities. Yet caring for persons with chronic disease, as opposed to acute illnesses or injuries, often requires that primary care providers spend more time with patients and keep up with evidence-based guidelines for the care of each specific chronic disease. A greater focus on prevention and management of chronic disease may thus have implications for how primary care is delivered. Questions may also arise about the integration with the public health system (e.g., different models may vary in who is responsible for immunizations).

*Integration with other parts of the health care system* is another important difference among models. Patients are vulnerable when they transition from one health care setting to another. Improved integration and coordination has been cited as a method to reduce wasted resources, fragmented care and patient dissatisfaction. However, there are some barriers to achieving this. For example, at the time of writing, no Canadian province had yet included physician services (including primary care) in their regional models (see Chapter 1, section 2.2.4, Regional Authorities in Canada), although Ontario had announced that it wished to begin moving in that direction. Note that many reformed models in many countries have sought to make PHC the gatekeeper to other sectors of the healthcare system (Saltman et al., 2006). In turn, this may require modifications in how PHC links to other sub-sectors, with potential facilitators including electronic health records and better administrative support. To the extent that PHC gatekeeping is seen as restricting patient choice, it may evoke patient dissatisfaction. Another key element,

which in theory should improve when patients are clearly linked (rostered) to an individual provider, is *continuity of care*.

**4. If you were to implement or expand on some of these elements, what barriers might you encounter? Which elements would involve the most resistance from key actors and stakeholders?**

The case illustrates that despite the fact that primary care reform has been on the government's agenda for decades, change has been incremental. As noted in Chapter 1, section 5.4, policy implementation can be complex. Fooks argued that one enabler was that Canadians are open to new models of health service delivery and already use and pay directly for services provided by non-physician health professionals, which means they should be open to having someone other than a physician as their first entry point (Fooks, 2004). Patients are also interested in health promotion and disease prevention activities. Another facilitator is that government also has control over some key policy levers, in that it already directly pays (through the provincial health insurance plan) the vast majority of physician fees. Physicians are already in place as an entry point to the system, and there are established mechanisms for negotiating fees between the provincial government and the provincial medical association. However, the other potential team members have relatively little power, and the FFS system does not work well for teams (and also usually does not pay directly for such expenses as professional education and communication among team members). Professional liability may also be an issue, since it tends to be based on individuals rather than teams. Sharing information may also be difficult to reconcile with privacy legislation. As noted above, there is no one best model, and different actors may prefer different payment and governance models. Ontario also has a history of using pilot projects to introduce reforms, which then may be easily reversed when new provincial governments are elected. Other barriers and facilitators result from the views of the key stakeholders.

**5. How should government involve key stakeholders in primary health care reform efforts?**

The following provides a summary of some of the key interests (see Chapter 1, section 4) in the primary care reform context.

The provincial *Ministry of Health and Long-Term Care* has several incentives for supporting PHC reform. In theory, reform could lead to cost-containment (in practice, costs have risen considerably). Primary care reform also provides opportunity for the government to maintain satisfaction of allied health professionals. The government has typically focused more on the short-term effects on public satisfaction than on the potential long-term effects of policy change, creating a start and stop approach to initiatives. Funding pilot projects also provide opponents with the opportunity to build and reverse policy direction when new government enters office.

Depending on the province, regional health authorities have responsibility for planning, funding and managing health services in their communities (see Chapter 1, section 2.2.4, Regional Authorities in Canada). At the time of writing, Ontario's model was a series of *Local Health Integration Networks (LHINs)*, which were intended to make the health care system more integrated and patient-centered. However, although the PHC provider is often considered the primary point of contact to the health care system, the LHINs have not been responsible for physician services. (Indeed, in most provinces, physician services have not been placed within regional authorities.) Payments to physicians are made by the provincial government. One

possibility is to create a greater role for the regional authorities, particularly if one believes that these regional bodies might be better able to understand the needs of the geographical populations that the PHC teams served and hence facilitate greater system integration. Indeed, as noted above, in 2012 the Ontario government suggested finding ways of making primary care part of the regional LHINs, although the precise mechanisms are still in the planning stages.

Physicians are very powerful stakeholders. Multiple physician organizations may be involved in the debate about PHC reform, including (but not restricted to) the Canadian Medical Association, the provincial medical association(s), College of Family Physicians of Canada, and such other groups as the Ontario College of Family Physicians and the Canadian Doctors for Medicare. They do not always agree. A number of organizations representing particular care models also exist; in Ontario, they include the Association of Ontario Health Centres (AOHC), and the Association of Family Health Teams of Ontario (AHFTO). Some of this role is institutionalized. For example, in Ontario, since 1997, the *Ontario Medical Association* (OMA) has had exclusive bargaining rights for physician services in the province, meaning that the government could not redistribute funding to alternative service delivery without the approval of the OMA. At the time of writing, the OMA was still the sole bargaining agent for all physicians, including those who choose to embrace reformed PHC models. Representatives of the OMA and the Ministry of Health are responsible for negotiating each multi-year provincial physician services agreement. These agreements have been seen as a barrier to PHC reform, as “new money” must be found for PHC reform to be implemented. The bipartite negotiations between the government and the medical association on policies related to PHC may also result in the exclusion of other health care providers (Fooks, 2004); Aggarwal, 2009).

Many individual physicians have been adverse to change, particularly if this would affect their autonomy (clinical, financial, and political). One advantage of the multiple models for individual physicians is that they can choose the practice model that best suits their financial, professional and personal needs.

Other *professions* and their *regulatory colleges* may also be involved, particularly when models include nurse practitioners, midwives, etc. on the team. Nurses, for example, have been very active; in Ontario, the Registered Nurses Association of Ontario (RNAO) has been heavily involved. Note that since there are different models suggested to serve different patient populations (including issues of number of patients, and geography), views may relate to the model. Some providers who were able to practice independently are eager to be allowed to directly bill the provincial health insurance plan, and be treated similarly to physicians. Other opportunities include opportunities for shared overhead, more effective patient care, and a possibility of extending the scope of publicly insured services. However these professions also see potential negatives in PHC reform, such as interprofessional tensions when working with physicians who see themselves as being “the boss” and loss of the private market should their services be publicly paid for (potentially at a lower rate).

Some *hospitals* have indicated an interest in providing space, management services, information technology assistance, and/or expertise to support PHC in their community, and recognize the potential for improved PHC to remove pressures from their hospitals.

There has been little political demand from the *public* for PHC reform, although there is pressure to ensure that everyone can find a PHC provider. Public attention has been focused on services that involve waiting lists and acute care services.

Political factors have had a large role in the lack of a “big bang” reform. Another potential barrier is the structure of professions. Historically, physicians as a profession have

often been in control. This historical pattern may raise conflicts when trying to implement collaboration where physicians' "turf" may be put in jeopardy. Other potential reforms that have been suggested include modifying professional education to stress team-based practice, and attention to how scope of practice is defined for the various provider groups.

**See also in Chapter 1:**

- 2.2.1 Federalism in Canada: *The Constitution Act, 1867*
- 2.2.4 Regional Authorities in Canada
- 2.3 Historical Institutionalism, Path Dependency and Policy Legacies
- 4 Interests
- 5.4 Policy Implementation
- 5.9 Insurance, Elasticity and Moral Hazard
- 6.1.1 Public and Private
- 6.1.2 Financing and Delivery
- 6.2 Payment Mechanisms and Incentives
- 6.3.2 Sickness Care Subsectors
- 6.4 Professionalism
- 7.1 Financing Health Care in Canada: Fiscal Federalism
- 7.2 *Canada Health Act*
- 9.1 Canadian Data

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## Chapter 12: Teaching Notes

### At Any Price? Paying for New Cancer Drugs

*Laurie Bourne, Rachna Chaudhary, David Ford, Olivia Hagemeyer,  
Christopher J. Longo, Elaine Meertens, and Raisa B. Deber*

#### Outcome

In 2008, the Ontario government announced that it would spend \$50 million to add three expensive cancer drugs, including Avastin, to the provincial drug plan (Ogilvie, 2008)

The benefits of Avastin continue to be disputed. In the case of colorectal cancer (CRC), it is clearly not curative; a study released in April 2009 found that Avastin is not effective at preventing recurrences of non-metastatic colon cancer following surgery (Allegra et al., 2011). It may also cause higher rates of high blood pressure, bleeding in the stomach and intestine, and intestinal perforations. There continue to be debates about whether the marginal benefits from using Avastin after surgery are worth the added toxicity. Some strongly believe that they are, and cancer groups have continued to press for expanded coverage.

Similar patterns of pressure to cover drug costs, coupled with difficulty in maintaining caps on what will be paid for, have occurred across Canada. The first province to cover Avastin was British Columbia (in January 2006). They initially capped payment at 12 cycles; in February 2008 this was expanded to 16 cycles and a Compassionate Access Program was established to consider extensions beyond 16 cycles. As of October 2008, it was expanded again; patients who reached 12 cycles could apply for an additional 12 cycles and then apply through the Compassionate Access Program for extensions beyond the 24 cycles if their disease had still not progressed. At that time, approximately 30% of patients requested funding beyond 12 cycles. The cost in 2008 was estimated at approximately \$6.3 million.

Newfoundland and Labrador approved funding for Avastin in July 2006, Quebec in October 2007, and Saskatchewan in January 2008. None capped the number of treatment cycles they would fund. Soon after Ontario's decision to fund this drug, Nova Scotia reversed its 2007 decision not to fund. In 2009, Alberta and New Brunswick also agreed to fund, with Manitoba making Avastin available on a case by case basis. Prince Edward Island had initially decided not to fund, but pressure (particularly from the Colorectal Association of Canada) led them to add Avastin for metastatic CRC, plus 9 other costly drugs, to their formulary, effective July 2, 2010. The programs in the different provinces varied (e.g., some had co-payments), but the total cost was significant.

Several expansions of the length of coverage have also occurred, both in Ontario, and in other provinces. In July 2009, the Ontario Ministry of Health and Long-Term Care announced that it would fund Avastin for 12 cycles; this was expanded in November 2009, for CRC patients who had responded well to that drug, as long as there was medical evidence from a physician indicating that there had been no disease progression. The criteria at that time allowed funded treatment with Avastin up to 24 cycles, with additional coverage available should the patient's doctor or oncologist so recommend. Deb Matthews, the Ontario Minister of Health and Long-Term Care, was quoted as saying: "I'm very pleased that we can now make Avastin more available to colorectal cancer patients. We remain committed to providing more cost-effective medication for people in Ontario, and reinvesting our savings in new and better drugs for everyone."

### **Avastin for Other Conditions**

Avastin has continued to be controversial. One example was the use of Avastin to treat metastatic breast cancer. The manufacturer's first US request for approval had cited an earlier clinical trial for breast cancer showing that Avastin did reduce tumor volumes and progression free survival time, but had no impact on survival time or on quality of life. On the basis of these findings, an outside expert advisory panel had voted 5 to 4 against approval. However, patient groups, and some oncologists, had disagreed. Initially, in 2008, the US FDA rejected the committee's advice, and did approve its use in metastatic breast cancer. In December 2010, however, the FDA reversed this decision and moved to withdraw approval for metastatic breast cancer, on the grounds that the risks from side effects outweighed the benefits.

### **Possible Points for Discussion:**

#### ***1. Who should make these decisions, and how? Discuss the potential roles of federal and provincial governments, cancer experts, and patients.***

One set of issues relates to who should be making these decisions. Patients are individuals, and their needs may vary. Several sets of ideas tend to clash. One is the extent to which decisions should be based on patient preferences, vs. expert opinion. A consumer sovereignty model would say that patients should be able to purchase whatever they would like. Taken to the extreme, pharmaceuticals should not need government approval to be sold. Recognition of "information asymmetry" (see Chapter 1, section 5.9, Insurance, Elasticity and Moral Hazard) may modify this view to varying degrees. For example, should people be able to purchase whatever drugs they want, even if the products are dangerous? Should regulators limit access to treatment that is not effective? Should people be allowed to buy ineffective products as long as there is full disclosure (truth in advertising)? How much autonomy should be given to providers in recommending treatments? What is the role for clinical guidelines, and to what extent should they bind treatment decisions? Since providers may also earn income from providing particular goods and services, how does one deal with the inherent conflict of interest (see Chapter 1, section 6.4, Professionalism)? What connection should there be between allowing a treatment to be purchased, and requiring a third party payer to foot the bill?

In Canada, there is also considerable debate about the potential roles of the federal government in encouraging block purchasing of drugs to negotiate lower prices. Canadian expenditures on pharmaceuticals have been increasing rapidly, and policy analysts have suggested that there may be considerable scope for savings (Anis, 2000; Gagnon & Hebert, 2010; Grootendorst & Hollis, 2011; Paris & Docteur, 2006; Skinner & Rovere, 2010). An array of policy alternatives have been suggested; recurrent suggestions are that providers (and payers) should make greater use of technology assessment to discourage use of ineffective goods and services, that public coverage of drug costs should be increased ("pharmacare"), and that block purchasing should be encouraged to lower costs. However, a sizeable proportion of pharmaceutical expenditure in Canada is paid privately (often through employer-based insurance) and governments have appeared reluctant to increase their own costs by extending coverage. As noted in the case, decisions about approving drugs are made at the federal level, but decisions about whether to pay for them are made by provincial governments, private insurers, and individual patients and their families.

There are also some legal issues that arise in Canada when provincial governments chose not to fund certain drugs. Flood has analyzed the issues relating to certain drugs that, for safety

reasons, must be provided in hospital-like settings. Under the *Canada Health Act* (see Chapter 1, section 7.2), pharmaceuticals administered in hospitals must be publicly covered. In turn, this may mean that even those patients who can afford to pay for unfunded drugs privately may have difficulty accessing them, depending on whether or not private-pay drugs can be legally administered within publicly funded hospitals; some have suggested that this situation may lead to a challenge under section 7 of the Canadian *Charter of Rights and Freedoms* (Flood & Hardcastle, 2007).

**2. *What are the views of key stakeholders including patients, physicians, pharmaceutical companies, private insurers, and the various levels of government. How might these different views be considered in decision making?***

As noted in Appendix C of the case, views vary across stakeholders. Physicians are often reluctant to deny patients benefits, however small or unlikely these benefits may be. They do not usually like to be put in the position of “bedside rationing”. There is also considerable variability in the treatment decisions made by individual providers. Patients, not surprisingly, faced with life or death situations, may wish to try anything that might help. As noted in Chapter 1, section 4 (Interests), there are also a series of “astroturf” groups (which pretend to be grass roots patient advocacy groups, but are often paid by corporations who stand to benefit from extensions of coverage). The media has been particularly apt to cover emotional pleas from patients urging third-party payers (public or private) to pay whatever price pharmaceutical companies demand for the newest drug.

The pharmaceutical companies are strong advocates of coverage. Note that they have an obligation to maximize return to their shareholders; this is facilitated by encouraging the maximum number of people to use each product, and charging whatever the market will bear. To the extent that demand for particular products is inelastic (which is particularly likely if life and death decisions are involved) and competition is low (particularly likely if the product is still under patent protection), prices may be very high and often unrelated to potential benefits.

Payers, including government, have dual goals. They do not want dissatisfied customers/voters, but also do not want to pay more than they have to. The extent to which cost-effectiveness should be considered in making coverage decisions is a continued source of controversy, particularly when it implies that particular lives are not “worth” saving.

**3. *Discuss the ethical implications of resource allocation for costly cancer drugs. How good does the evidence need to be? What should be done until the evidence is available?***

One challenge is how to reconcile several seemingly contradictory moral premises. On the one hand, many would agree that human life is priceless, and that to think otherwise is to detract from the dignity of the patient. On the other hand, most would also agree that resources are finite and society must decide how best to distribute them (see also Chapter 1, section 3.6.3, Resource Allocation/Rationing).

One ethical principle is sometimes called the Rule of Rescue. It calls on us to rescue identifiable individuals in immediate peril, regardless of the cost. The tension between cost effectiveness and the Rule of Rescue can generate serious ethical and political difficulties for public policy makers.

Another ethical debate concerns what society owes its members (see Chapter 1, section 3.6, Ethical Frameworks). At one extreme, libertarians might argue that they should not be

compelled to pay for costs incurred by others. Where the line should be drawn is by no means obvious.

#### ***4. Discuss the role of cost-effectiveness evaluations in the drug approval process.***

As noted in Appendix E to the case, a systematic review and economic evaluation of bevacizumab and cetuximab for the treatment of metastatic CRC was conducted for the UK technology assessment body NICE (Tappenden et al., 2007a, 2007b). Note that it is very difficult to do these computations, in part because the manufacturers have withheld most data about its outcomes as trade secrets. NICE concluded that the probability that adding Avastin to the existing chemotherapy approaches would be cost-effective (which they defined as having a marginal cost utility of less than £30,000 pounds per QALY gained) was close to zero.

Note that the methods of cost-effectiveness analysis can be used to compute the incremental cost-effectiveness ratio (ICER), that is, the added cost to achieve one more unit of outcome. ICER is computed by subtracting the costs of the two alternatives, and dividing them by the difference in outcomes. In the example in Appendix E to the case, the difference in costs of model 1 (IFL with or without Avastin) was \$19,360.73 to purchase an additional 0.41 years (or .31 QALYs). Sensitivity analysis can also be performed to see what would happen if key variables changed (e.g., changes in costs, changes in life years gained, etc.).

Note that there are a number of ways to measure outcomes. Often, they measure only a portion of the impact, rather than the overall effect (e.g., are all life years the same, or is one interested in disease-free progression only?). Mortality as a measure may be affected by deaths from causes unrelated to that disease or treatment. Quality of life is also complex to measure. As noted in Chapter 1, section 8.1 (Economic Analysis), there is an extensive literature examining this subject (Culyer & Newhouse, 2000; Drummond et al., 2005; Gold et al., 1996).

However, there is little dispute that a category of pharmaceuticals, including Avastin, involves very high costs for relatively small benefits. A US study (Brock, 2006) criticized drug companies for the high prices they were charging. It noted that Genentech priced Avastin based on “the value of innovation, and the value of new therapies” rather than on the cost of production. Its estimate was that the cost per QALY was over \$230,000 if the benefits and usage were assumed to be the same for colon cancer as for lung and breast cancer, assuming that the drug would be taken for an average of 11 months and add five months to life. Another study surveyed 139 academic medical oncologists; only 25% thought that Avastin provided good value (Nadler et al., 2006).

If one agrees that this drug fails most common estimates of cost effectiveness, one must then turn to the ethical question about whether that is an appropriate metric. If one believes that life has infinite value, economic analysis is irrelevant. Note that in the Ontario ombudsman’s report (Marin, 2009), little mention was made that the paucity of evidence about when the drug is not useful also applied to a lack of evidence of its benefits; instead, the ombudsman strongly implied that the burden of proof should lie with those attempting to contain costs. Many agree with him. One notable development is the decision by the UK government to make NICE decisions advisory only; commentators have suggested that this will make it more likely that expensive drugs which do not pass the cost-effectiveness criteria will be funded.

The class may wish to discuss the ethical issues involved. Should the patient’s age matter? Anticipated survival time? Quality of life? Income? Would better information and emotional support help people make better decisions (and what would constitute a good decision)?

**See also in Chapter 1:**

- 3.6 Ethical Frameworks
- 3.6.3 Resource Allocation/Rationing
- 4 Interests
- 5.9 Insurance, Elasticity and Moral Hazard
- 6.3.2 Sickness Care Subsectors
- 6.4 Professionalism
- 7.2 *Canada Health Act*
- 8.1 Economic Analysis: Cost-effectiveness
- 8.3.2 Risk Perception

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**The following websites may also be helpful:**

Canadian Cancer Society <http://www.cancer.ca>,

Cancer Care Ontario: <http://www.cancercare.on.ca>. Website also includes information on the Cancer Drug Approval Process <http://www.cancercare.on.ca/cms/one.aspx?pageId=11815> and a (since archived) 2008 guideline report on *The role of Bevacizumab (Avastin) combined with chemotherapy in the treatment of patients with advanced colorectal cancer*. <https://www.cancercare.on.ca/common/pages/UserFile.aspx?fileId=13998>.

International Society for Pharmacoeconomics and Outcomes Research <http://www.ispor.org> includes roadmaps of the technology assessment process in all member countries, including Canada (<http://www.ispor.org/HTARoadMaps/CanadaPharm.asp>).

National Cancer Institute at the National Institute of Health, Cancer Drug Information <http://www.cancer.gov/cancertopics/druginfo/fda-bevacizumab>

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Ontario Ministry of Health and Long-Term Care, Drug Submissions

[http://www.health.gov.on.ca/english/providers/program/drugs/drug\\_submissions/inter\\_oncology\\_drugs.html](http://www.health.gov.on.ca/english/providers/program/drugs/drug_submissions/inter_oncology_drugs.html)

## Chapter 13: Teaching Notes

### What to Do with the Queue?

*John Blake, Daniel Bolland, Ian Dawe, Brenda Gamble, Gunita Mitera,  
Natalie (Wajs) Rashkovan, Somayeh Sadat, Kenneth Van Wyk, and  
Raisa B. Deber*

#### Outcome

At the time of the case, PMH did briefly close its doors to new patient referrals; many of these patients were sent to other centers. The Ontario Ministry of Health then appointed a Cancer Manpower Committee; its 1991 report made several human resources recommendations, but these were not acted on.

The problem remained. A very similar crisis occurred in 1999. According to a September 30, 1999 article by Rita Daly in the *Toronto Star*, the same piece-meal solutions were being used a decade later “to combat a backlog of cancer patients waiting for radiation treatment”. Shortages of radiation therapists, oncologists and physicists had resulted in a situation where only 20 per cent of patients were being treated within the maximum four-week period recommended by the Canadian Association of Radiation Oncologists. Almost half were waiting longer than 8 weeks. The short term solution was similar; Cancer Care Ontario, the new coordinating body, again sent cancer patients to other centres for radiation. The story noted that 83 patients had gone to the Thunder Bay Ontario cancer centre (a community nearly 1300 km away, near the Manitoba border), and 372 patients (at a much higher cost) to the US. (Indeed, the provincial government spent about \$30 million to send patients to the US for radiation treatment; it cost about \$375,000 per week to send 20 patients there.)

The provincial government also addressed the HHR issues. It agreed to spend \$15.5 million annually to train new physicists and therapists and recruit staff from Great Britain, Australia and New Zealand. It hired 57 radiation therapists from Australia and New Zealand; after allowing for attrition, this represented a net gain of 17 therapists. It also attempted to lure back RTs who had left for the US. For the longer run, it launched a new second entry 3-year training program at the Michener Institute for Applied Health Sciences in Toronto (located very near the PMH site) in partnership with the University of Toronto. (This partially compensated for the closure of the old in-hospital diploma program.) Existing therapists were offered a 10% raise, boosting their salaries to \$55,000. In addition, all centres were running their radiation machines at least eight hours a day, and sometimes more.

The result was a slow shrinkage in the wait list and in the number still waiting for treatment over and above the recommended four-week period, but this was still seen as unacceptable.

A related response was to improve data gathering. Cancer Care Ontario began to compile detailed reports about waiting times centrally. Over the 1992-2002 period, they confirmed that these wait times had continued to increase, and there were concerns that people were receiving sub-optimal quality of care.

A longer-term response was to set up wait time strategies. A federal/provincial/territorial committee had identified five healthcare services to target for wait time reduction; cancer was included as one of these priority areas. In December, 2005, the Provincial and Territorial health ministers established a set of wait time benchmarks. For radiotherapy, they divided the waiting period into two segments: 1) *Referral to consult* (the time between a referral to a specialist to the

time that specialist consults with the patient); and 2) *Ready to treat to treatment* (the time from when the specialist is confident the patient is ready to begin treatment to the time the patient receives treatment). A benchmark for radiation treatment was set; patients were to receive the first treatment within four weeks (28 days) of being ready to treat.

According to the material posted on the Cancer Care Ontario website (Cancer Care Ontario, 2013), the strategy has been effective. Wait times for radiation have been continually improving since 2003. As they noted: “For the period of April to September 2009, 96.0% of Ontario patients started radiation treatment within four weeks of being ready to treat, compared with 76.2% in September 2005, an improvement of 19.8%.”

### **Possible Points for Discussion:**

#### ***1. Suggest options for dealing with this issue. What are their advantages and disadvantages?***

The potential options include:

Option A. *Increase capacity.* Because one major rate-limiting step was RTs, increasing capacity would require the recruitment and retention of RTs. A number of options for increasing capacity were available, both short and long term. Short-term measures could include various combinations of increasing capacity using the existing staff (e.g., longer work days, more shifts, paying overtime) and/or recruiting overseas and discouraging personnel/technology exchanges with underdeveloped countries (which presented its own ethical issues). Longer-term measures could involve training more RTs, either through increasing the capacity of the existing programs (which would require finding more units to treat/train on) and/or through new programs. A related option was whether these training models would be combined with policies to lower credentials (e.g., shortened training programs, more flexible general training, and/or using alternate categories of workers) or to increase credentials and skill levels (which is what the new programs did). Another potential policy lever was financial; classical economic models would predict that paying higher wages should improve recruitment and retention. One could also allow private managers to run an after-hours clinic in an existing department; this would allow them to pay more to their workers, without putting pressure on the hospital to extend similar benefits to other employees.

Option B. *Cap number of patients.* Those who could not be treated at PMH could be sent elsewhere (to other centres in Ontario, elsewhere in Canada, and/or the United States). The hospital might also choose to refuse foreign patients (or even refuse patients coming from outside of their catchment area). They might also select less complex cases that could be planned and treated relatively quickly compared to the more complex cases. For example, some types of cancer (including breast cancer and prostate cancer) are both relatively common and relatively less complex to treat.

Option C. *Change the balance* between palliative and radical treatment. One possibility would be to focus on patients with better prognoses and reduce care for palliative care patients. Alternatively, they could concentrate on palliative patients (and make their wait list numbers look better, since these patients needed fewer fractions).

Option D. *Improve management of processes.* Seemingly minor innovations, such as instituting a single registry and ensuring that all necessary tests were booked in a coordinated fashion, might ensure that the available slots were used to their maximum capacity. One might also consider whether the existing funding/incentive structures, which were often based on

global budgets, discouraged providers from increasing volume (see Chapter 1, Section 6.2, Payment Mechanisms and Incentives).

Option E. Generate *additional revenues* through medical tourism. This option would offer after-hours services to people from other countries who would be required to pay out of pocket for their treatment services. Treatment for these individuals would be provided after-hours. The profit generated could be reinvested in the hospital to update equipment and/or to hire additional RTs. This increased capacity could then be used to reduce wait times for Canadian patients.

Option F. *Do nothing* and hope things would get better.

## **2. Discuss the potential options in terms of queuing theory. Which variables are they addressing?**

Queuing theory can be used to analyze the impact of possible options (Carter & Price, 2001). The equation given in the case notes that mathematical stability requires capacity to be greater than demand. As noted in the example below, it is evident that 10 machines operating 8 hours per day is the minimum requirement for ensuring mathematical stability (and indeed, running a slight surplus of capacity compared to demand). 10 machines operating 10 hours per day would run a larger surplus ( $400-302 = 98$  fractions), whereas 8 machines operating 8 hours per day would incur a deficit ( $256-302 = -48$  fractions).

Queuing theory suggests that policies might be adopted to affect any or all of:

a) The number of servers in the system. Adding new machines, or new centres, would affect capacity. This is option A (above); option E might also address this approach, depending on how the profits were used.

b) The rate at which customers arrive. This is related to option B, and might include options relating to diverting people to other centres. (In the long run, there might be some scope for reducing demand by disease prevention, but this would be unlikely to affect the demand in the short- or even medium-term.)

c) The manner in which customers are selected (queue discipline). This is related to option C. It also includes elements of appropriateness. Note that this is far less of an issue for radiotherapy (where most of those referred for service would indeed be likely to benefit), than it is for more discretionary services (e.g., diagnostic imaging). However, it is possible that other forms of pain management might be equally effective for some patients, lessening the need for radiotherapy.

d) The rate at which customers are served (option D). This might include various ways to streamline operations and eliminate bottlenecks. For example, one hospital found that by staggering the start times for their operations, they were able to make better use of their recovery rooms. Improvements could be made in how people are scheduled for service that would reduce downtime. This sort of management improvement has enormous scope for improving the efficiency of care delivery. As one example, it can often be more efficient to set up a single point of entry, which translates into replacing multiple queues by a single queue.

An additional complexity occurs when queuing systems consist of a series, or sequence, of stages. In stage systems, the customer enters the first stage and gets a portion of the service, before being able to move on to the second stage, and so on. In the case of radiotherapy, for example, patients need to be diagnosed, given a treatment plan, and receive a simulator diagnostic X-ray to calibrate the actual field and dosage required before they receive the initial dose. This model is called a “simple serial multi-stage queuing system”. The speed of the flow of

customers through the stages will be determined by the slowest stage. This slowest stage is also known as the “rate determining stage” or “bottleneck” of the system, and would probably be the first target for quality improvement. In some centres, radiation consultation, treatment planning, and quality assurance have been co-located in the same physical space to reduce the time from consultation to treatment.

### Case Example: Applying Queuing Theory

The instructor may wish to work a case example in more detail. At the time of the case, assume that PMH used the following queuing method:

- a) An individual is diagnosed with a malignancy and is referred to PMH.
- b) The individual receives an outpatient visit within a week of referral. This visit involves basic medical investigation and evaluation of the disease. If necessary, a radiation therapy course of action is planned by a RT, radiation oncologist, and clinical physicist. The radiation oncologist uses a CT scan, MRI, PET scan or X-ray to localize the tumour. A simulator diagnostic X-ray is made which is calibrated to the various radiation therapy machines to find the actual field of radiation. The RT and clinical physicist produces a dose calculation that defines the actual dosage required.
- c) The patient is then slotted for the next available machine appropriate for the treatment plan. (One simplification for this example is that we will assume that all machines are equal. In fact, at the time, machines could be Cobalt 60, Gamma ray or High Energy, and different machines treated different types of cancer.) If the required machine is not available, the patient joins a waiting list.
- d) While waiting in the queue, the patient must be at least seen once a week. If the oncologist determines that the patient is rapidly deteriorating, the patient is moved up the queue.
- e) The oncologist's decision is made solely on medical criteria.

*Capacity Assumptions:* Each radiotherapy treatment, or dose fraction, requires 15 minutes of machine time. PMH has 10 machines. Each machine is staffed five days per week, 50 weeks per year. Using these assumptions capacity can be estimated as follows:

At *Maximum Capacity*: (10 Machines; 10 Hours per Day),  
 $\text{Capacity} = 10 \text{ machines} * 4 \text{ fractions/hour} * 10 \text{ hours/day} * 250 \text{ days/year} = 100,000$   
 fractions/annum  
 = 400 fractions/day.

At *Sustainable Capacity*: (10 Machines; 8 Hours per Day),  
 $\text{Capacity} = 10 \text{ machines} * 4 \text{ fractions/hour} * 8 \text{ hours/day} * 250 \text{ days/year} = 80,000$   
 fractions/annum  
 = 320 fractions/day.

At *Minimum Capacity*: (8 Machines; 8 Hours per Day),  
 $\text{Capacity} = 8 \text{ machines} * 4 \text{ fractions/hour} * 8 \text{ hours/day} * 250 \text{ days/year} = 64,000$   
 fractions/annum  
 = 256 fractions/day.

*Demand Assumptions:* Forty-five percent of all cancer patients undergo radiotherapy. Of these patients, approximately 50% are prescribed radical therapy and 50% are prescribed palliative therapy. Patients undergoing radical therapy receive an average of 30 fractions per course of treatment, while patients prescribed palliative therapy undergo an average of 10 fractions per course of treatment. Approximately 20% of all patients require re-treatment. Annual

new patient volume at PMH is 7,000 patients. Using these assumptions, demand can be calculated as follows:

At 7,000 New Referrals per Annum,  
 Radiotherapy Patients = 7,000 referrals \* 0.45 prescription rate = 3,150 patients/annum;  
 Radical Cases = 3,150 RT patients \* 0.5 radical treat rate = 1,575 patients/annum;  
 Palliative Cases = 3,150 RT patients \* 0.5 palliative treat rate = 1,575 patients/annum;  
 New Demand = (1,575 radical treatment cases \* 30 fractions/patient) + (1,575 palliative cases \* 10 fractions/patient) = 63,000 fractions/annum;  
 Re-treat Demand = 63,000 fractions \* 0.2 re-treat rate = 12,600 fractions/annum;  
 Total Demand = 63,000 new fractions + 12,600 re-treat fractions = 75,600 fractions/annum = 302 fractions/day (based on 250 days).

*Supply Less Demand:* Mathematical stability requires capacity to be greater than or equal to demand. From the capacities and demand estimated above, it is evident that 10 machines operating 8 hours per day is the minimum requirement for ensuring mathematical stability.

At maximum capacity: 400 fractions/day - 302 fractions/day = 98 fractions/day (surplus);  
 At sustainable capacity: 320 fractions/day - 302 fractions/day = 18 fractions/day (surplus);  
 At minimum capacity: 256 fractions/day - 302 fractions/day = - 46 fractions/day (deficit).

### ***3. Discuss the implications of various ways of paying providers, and how they affect the incentives to see/not see patients.***

As noted in Chapter 1, section 6.2 (Payment Mechanisms and Incentives), there is no perfect way to pay providers. Depending on the type of service and patient needs, different incentives may be associated with quality issues related to overuse, underuse, and misuse (Institute of Medicine, 2001). Some financing models give incentives to do more (e.g., fee-for-service); others give incentives to do less (e.g., global budgets, capitation). In Canada, hospitals have largely been paid on the basis of global budgets; this gives them a financial incentive to do as little care as possible (to stay within the budget), which hopefully will be modified by their incentives as health professionals to ensure high quality of care for their patients.

This highlights one key problem with analyzing wait lists; it is essential to ensure that there is a mechanism to make sure that the care provided is appropriate. Otherwise, badly thought out incentives can encourage overuse. This has indeed been an issue for some services (Deber, 2008). However, overuse is less likely to be a problem for radiation therapy, since professionals would not be likely to suggest unnecessary doses. The PMH radiation oncologists were paid on salary through group practices, and did not have economic incentives to increase the number of patients they saw, although, as professionals, they were expected to ensure their patients were well cared for. (In some centres, the payment approach has since changed to fee-for-service.) Similarly, RTs would be salaried by the institution where they worked. Increasingly, payers are experimenting with service based funding for those services where increased productivity is wanted, recognizing that this may also provide incentives for over-use.

### ***4. Discuss health human resources planning as it affects the ability to meet demands for radiotherapy, with particular emphasis on RTs.***

As noted in Chapter 1, section 8.4 (Health Human Resources), HHR planning issues include the mix of personnel to use, how much they are paid, and their working conditions. Estimates of how many providers are needed are complex, and often dependent upon the assumptions made. Historically, there have been switches from perceptions of surplus to

perceptions of shortage. These boom-bust cycles can be expensive, and counterproductive. The impact may also vary depending on how providers are paid, with those working fee-for-service as relatively independent providers (e.g., physicians) more able to withstand government cutbacks than those downsized because they worked for organizations whose funding was constrained during economic difficulties.

As noted in Chapter 1, section 8.4.1 (Projecting Supply and Demand) most models estimate supply using a “stock and flow” model. In this approach, new providers are added to the existing stock through new graduates from training programs, immigration, and increased labour force participation (e.g., return to work). They are subtracted through death, retirement, emigration, and decreased labour force participation (Maynard, 2006). The policy levers accordingly include changing the number trained, encouraging/discouraging foreign-trained workers, and influencing labour force participation (recruitment and retention).

### ***5. Discuss the ethical issues involved in dealing with this issue***

Chapter 1, section 3.6.3 (Resource Allocation/Rationing) discusses some of the dilemmas involved in prioritizing and rationing. For example, should those patients with a potential for cure have priority over those for whom treatment is palliative? Alternatively should after hours treatment be made available to foreign patients to increase the capacity for Canadian patients?

Another issue is who is responsible for ensuring that patients are seen, and for ensuring follow-up care for those referred to more distant centres. If delivery is not coordinated, patients may fall through the cracks.

### **See also in Chapter 1:**

- 3.6.3 Resource Allocation/Rationing
- 6.2 Payment Mechanisms and Incentives
- 6.3.2 Sickness Care Subsectors
- 8.4 Health Human Resources
- 8.4.1 Projecting Supply and Demand

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**The following websites may also be useful:**

Canadian Cancer Society. Site includes yearly report on Canadian cancer statistics  
<http://www.cancer.ca/en/cancer-information/cancer-101/canadian-cancer-statistics-publication/?region=on>



## **Chapter 14: Teaching Notes**

### **Down the Tubes: Should In Vitro Fertilization Be Insured in Ontario?**

*Talar Boyajian, Susan Bronskill, Sheryl Farrar, Erin Gilbert, Seija K. Kromm, Lise Labrecque, Mina Mawani, Wendy Medved, Phyllis Tanaka, Dan Tassie, Judy Verbeeten, and Raisa B. Deber*

#### **Outcome**

As noted in the case, the Ontario Joint Review Panel (JRP) had recommended de-insuring IVF procedures for all infertility diagnoses except for bilateral fallopian tube blockage, and Ontario had implemented this recommendation in 1994. In 2010, Quebec had agreed to directly fund IVF, and Manitoba had agreed to subsidize up to 40% of the costs. At the time of writing, despite a number of groups and reports urging that IVF funding be restored, Ontario and most other provinces were still not funding IVF for most people.

#### **Suggested Questions for Discussion:**

***1. What is infertility? Is it a disease or a social condition? Compare and contrast various alternatives that might be used by families wanting a child.***

There is some debate on whether infertility should be viewed as a medical disease or a social condition. The World Health Organization formally recognizes infertility as a “disease of the reproductive system”. Others argue that it is a social condition, resulting where there is a strong desire to have children, with social stigma and emotional pain often associated with not being able to conceive. Public opinion surveys in many countries have shown strong support for assisting couples to have their own biological children. For example, in the 1990s, the Royal Commission on New Reproductive Technologies had conducted a survey, which found 80% approval for IVF when it involved the couple’s own egg and sperm (Canada Royal Commission on New Reproductive Technologies, 1993).

An increasing number of Canadians are affected by this issue. The Expert Panel on Infertility and Adoption estimated that the number of Ontario patients who billed the Ontario Health Insurance Plan (OHIP) for diagnosis of infertility, and/or those few diagnoses still publicly insured (e.g. tubal surgery, IUI or IVF for bilaterally blocked tubes), had steadily increased, from 66,255 in 2000, to 75,124 in 2004 (Expert Panel on Infertility and Adoption, 2009). Presumably, there were many more paying privately, or wishing such treatment but unable to pay for it.

One set of ethical disputes relates to whether women are being pressured to reproduce. Some suggest that IVF reinforces a social expectation that all women should have children rather than pursue other goals; others argue that IVF empowers women by allowing them the choice to delay childbearing in order to pursue a career. Expert opinion varies as to when these expectations are realistic, and when postponing childbirth increases risks to the mother and children.

Another set of disputes relates to the importance of having a biological child. For example, some have argued that if infertile couples desperately want a baby, they should adopt a

child needing a home. That view would argue that public funds should not be spent for fertility treatments, but might support adoption. A related question involves defining parenthood. IVF may involve as many as five individuals: the genetic mother (egg donor), genetic father (sperm donor), the gestational carrier, and the parents who would raise the child. There is the potential for legal and ethical ambiguity, particularly if some parties no longer wish to comply with prior agreements (e.g., if the potential parents no longer want the child, or if the gestational mother does not want to surrender it). Similarly, difficult ethical dilemmas arise surrounding the protection of the identity of anonymous sperm or egg donors, and whether the children have a right to know their genetic parents.

Another debate concerns whether IVF is “medicalizing” infertility, and the extent to which medical research, education and clinical practice should focus on protecting fertility rather than treating infertility. Studies have shown that many cases of infertility with no identifiable etiology, collectively termed idiopathic infertility, are caused by psychosocial factors such as stress. In such cases, many have argued that less invasive options such as counselling should be explored first, and that medicalizing infertility may hinder addressing the root causes. According to this paradigm, the millions of dollars that would be spent on public IVF treatment could be better spent on efforts to protect fertility or address its causes in a preventative manner.

The *alternatives* available to families wanting a child could include: normal pregnancy, adoption, fostering, and/or assisted reproduction. The class may wish to note the differences in such factors as: the cost associated with bringing the child into the family; the scrutiny given to whether the household should be “allowed” to have the child; and who pays for the costs associated with that child. In general, normal pregnancy is considered a personal matter unless there are egregious factors seen to place the child at risk. Adoption involves considerable scrutiny of the suitability of the home and potential parents. Fostering leaves most costs of bringing up the child as the responsibility of the state. One ongoing debate is whether assisted reproduction should be seen as more like normal childbirth or adoption.

***2. What, if any, aspects of IVF should be regulated, and by whom? What are the similarities and differences between: “natural” conception, assisted reproduction, and adoption? Which factors should/should not be taken into account in determining whether an individual or couple should have a child? Prospective parents’ history of violence? Single parenthood? Sexual orientation? Parental income? Age of prospective parents?***

Views about reproduction reflect differences in underlying ideas. As Chapter 1, section 3.4 (Framing) notes, similar questions can be defined in very different ways. As noted above, having a child can be seen as an intensely personal experience, where individual liberty should prevail unless there is strong evidence of potential harm to the child. “Natural” conception is thus not subject to state interference, although should the child be endangered, the authorities may step in. In contrast, the decision to adopt a child places emphasis on the best interests of the child, and considerable effort may go into scrutinizing its potential home. The class may wish to discuss which of these situations would apply to assisted reproduction. (One possibility is that it depends on who pays for it, with state-paid services falling into the adoption paradigm and individually paid services into the conception paradigm. Other possibilities could also be defended.) Another highly contentious issue in some jurisdictions is whether single people, or same sex couples should be permitted to form families (through adoption, and/or assisted reproduction).

This debate also fuels the debate about which, if any, aspects of assisted reproduction should be *regulated* (see Chapter 1, section 5.2.1, Regulation). The calls for regulation arose from concerns about the actions of fertility clinics, particularly in the US. One striking example was the case of Octo-mom, where a single mother, who already had 6 young children, gave birth to octuplets; all 14 children were born through assisted reproduction. Implanting so many embryos posed considerable risk to both mother and children. (Her doctor was eventually disciplined for a series of similar questionable actions. In 2011 he lost his license to practice medicine in California.) Other ethical issues that have been raised around IVF include views towards: selection of embryos for sex or genetic traits (“designer babies”), maternal age (some clinics have implanted women >50 years old), posthumous reproduction (using gametes of a dead person), and/or the potential for extracorporeal gestation (gestation in an artificial womb). Whether such practices should be regulated, and if so, by whom, are unclear.

In Canada, the 2009 Ontario Expert Panel on Infertility and Adoption had noted that there were no common national or provincial standards for IVF treatment. Clinics did not need to be licensed, and accreditation was not mandatory. Many, but not all IVF clinics and fertility centres chose to be accredited by Accreditation Canada (Expert Panel on Infertility and Adoption, 2009). However, the health professionals who provide the fertility services are members of regulated professions, and are accordingly expected to follow whatever practice guidelines might be set by their provincial regulatory colleges (see Chapter 1, section 6.4, Professionalism). In general, there is minimal enforcement of whatever guidelines exist. In some cases, guidelines may be set by the national professional bodies; because these organizations are involved in setting the qualifications needed to be designated as belonging to a recognized sub-specialty, but are not involved in determining who will be licensed to practice within a particular province/territory, their guidelines tend to be advisory rather than binding. As one example, in 2006, the Society of Obstetricians and Gynaecologists of Canada (the national professional body) had released a guideline limiting the number of embryos that should be transferred during IVF, but this was widely ignored. The Expert Panel noted that only 112 women of 4,022 who had received IVF in Ontario in 2007 (2.8%) had agreed to have a single embryo transfer (Expert Panel on Infertility and Adoption, 2009).

The question of who might regulate professional practice falls into the grey zone between federal jurisdiction and provincial jurisdiction (see Chapter 1, section 2.2.1, Federalism in Canada). In 2004, the federal government passed the *Assisted Human Reproduction Act*. This Act established a regulatory agency, Assisted Human Reproduction Canada, with a mandate to “protect and promote the health and safety, and the human dignity and human rights of Canadians and to foster the application of ethical principles”. Although that agency was set up in 2006, it made very few regulations. The *Assisted Human Reproduction Act* had attempted to bypass provincial jurisdiction over health care by using the criminal law power. Some provinces (particularly Quebec) disagreed, and challenged the *Act* in court. Among the provisions of the *Act* was to deem one category of activities to be prohibited, on the grounds that they were ethically unacceptable and/or posed significant risks to the health and safety of Canadians. This included cloning, sex selection, and making human-animal hybrids. In addition, the *Act* prohibited using gametes or in vitro embryos without the consent of the donor, obtaining gametes from people under age 18 (except to preserve them for their own subsequent use), and commercialization by “paying, offering to pay, or advertising payment for sperm, eggs or in vitro embryos from donors or for the services of surrogate mothers (including payment to a third party

for arranging for the services of a surrogate mother)’’ other than reimbursement for legitimate expenses.

However, another portion of the *Act* set out controlled activities, which would be regulated, but were permissible if performed in accordance with the regulations, and by a licensed clinic or individual in licensed premises. This category included such services as *in vitro* fertilization (IVF); intra-cytoplasmic sperm injection (ICSI); intrauterine insemination (IUI); donor insemination; egg donation; transfer of an *in vitro* embryo; and research on *in vitro* embryos. In 2010, the Supreme Court of Canada (in a split decision) struck down all of the regulations relating to controlled activities, on the grounds that provinces have exclusive authority to regulate fertility clinics, license doctors, and set policies (should they choose to do so) about reimbursing sperm and egg donors for their expenses, deciding how many embryos to implant, and so on. The court decision ruled that the federal government had the power to designate prohibited activities (including banning the commercial trade of eggs, sperm and embryos), but that the federal government could not license fertility doctors or regulate their practices. Provinces could step in, but at the time of writing there was little control over the activities of fertility clinics beyond the controls exercised by the provincial professional regulatory colleges. As a result of the court decision, it appeared likely that most control would rest with the professional judgment of providers with the possibility of (piecemeal) provincial regulation should an issue be seen as sufficiently high on the policy agenda of the particular province/territory. (In general, this would probably require waiting for an egregious example of questionable practice to occur). In its 2012 budget, the federal government abolished Assisted Human Reproduction Canada.

Note that many jurisdictions that do fund IVF have linked their funding to regulations about how many embryos can be implanted at a single time. There are also concerns about possible exploitation of poor women, particularly if commercialization of egg donation or surrogacy is permitted. Here, jurisdiction is a major issue. For example, even if rules are set up in one jurisdiction, there is little to prevent “medical tourism” whereby people initially obtain services from other jurisdictions with less rigorous rules, but return to their home jurisdiction for follow-up care.

### ***3. Is IVF something the public should pay for? What factors or criteria should be considered in deciding whether to publicly fund health services, including infertility?***

One of the most commonly used arguments in support of public funding of IVF is that infertility is a disease or medical condition, and therefore its treatment should be considered “medically necessary” under the *Canada Health Act (CHA)*. Others argue that infertility does not cause morbidity or mortality therefore treatment should not be classified as “medically necessary”. A 2010 article reviewed various approaches to considering whether IVF should qualify for public financing (Mladovsky & Sorenson, 2010). One rationale draws on Daniels’ conceptualization that medical needs arise where there is a disruption in the normal human function, which results in a limitation of fair equality of opportunity (McMillan, 2001). Fair equality of opportunity is important because a person requires it to be able to live a good life, and inequities based on ability to pay would thus be inappropriate. Another argument that has been put forth to support universal public funding of IVF is based on the rationale of human rights. IVF coverage has been cast as a “right to health”, “right to reproduce”, and/or “right to reproductive choices” (Giacomini et al., 2000; Mladovsky & Sorenson, 2010). Yet another rationale for public funding of IVF has appealed to the need for more children to offset the

impact of population aging. Internationally, Korea and Estonia have used this rationale to reimburse the costs of IVF. Note that this rationale can have potentially xenophobic elements, particularly if the argument is based on the idea that the society needs “more people” from certain ethnocultural backgrounds.

There have been several efforts by infertile couples in Canada to use the courts to challenge provincial legislation excluding IVF from public funding, based on equality rights. In 1999 a Nova Scotia couple sued the province on the basis that the failure to fund IVF for infertile couples was discriminatory and therefore violated their equality rights under section 15(1) of the *Canadian Charter of Rights and Freedoms* (see Chapter 1, section 2.2.2) and the principle of comprehensiveness under the *Canada Health Act*. The trial level court rejected the couple’s request on the basis that the procedure was not “medically required” because infertility is not an illness or disease (Moulton, 2000). The Nova Scotia Court of Appeal overturned this finding, and ruled that IVF procedures did qualify as medically necessary. Their ruling said that failure to insure IVF thus did deny equal benefit of the law to the appellants and this denial of treatment was discriminatory, constituting a breach of section 15(1) of the *Charter*. However, the couple still lost; the appellate court held that this breach was justified under section 1 of the *Charter* as a reasonable limit prescribed by law in a free and democratic society. The Court basically decided that the allocation of scarce public resources to competing interests should be left as a government decision, rather than be made by the courts (Washenfelter, 2003).

Another effort by Terry Buffett, a member of the Canadian military who appealed his denial of coverage for IVF to the Canadian Human Rights Commission, was more successful. The military argued against coverage, largely on the grounds that the treatment would be for his wife, who was not a member of the Canadian Forces and hence, although being covered under the relevant provincial health plan, had no entitlement to coverage under his military health plan. Buffett argued that the cause for the infertility was his low sperm count, and hence that he was the patient. Because the military had covered IVF treatment for women since 1997 (and only because the female soldier who had launched the complaint had been living in Ontario, the only province that covered IVF, and hence could make the argument that she would have been entitled to coverage for her particular diagnosis had she not been in the military), the commission held that this was a clear example of discrimination on the basis of sex, and held that, as long as women received coverage, men must also (Canadian Human Rights Tribunal, 2006).

Another case, still not decided at the time of writing, was filed in August 2009; Amir Attaran and his wife Ana Ilha filed a complaint about the Ontario Ministry of Health and Long-Term Care (MOHLTC) with the Human Rights Tribunal in Ontario alleging that the province’s current policy of funding IVF for some but not all indications was discriminatory (on the basis of disability and sex). Attaran was a law professor at the University of Ottawa. Their battle centred around equitable access to IVF treatment, arguing that IVF should be funded for all individuals, regardless of diagnosis, since they all suffered from the same condition (infertility) which had been deemed medically necessary by the MOHLTC. The case was merged with similar cases from two other plaintiffs (Robert Mesher and Betty Lobo). Subsequently, both Mesher and Lobo withdrew their applications. On September 2, 2011, the tribunal issued an interim decision putting the case into abeyance until April 12, 2012 (Human Rights Tribunal of Ontario, 2011). At the time of writing, although that date had passed, no decision had yet been published.

To the extent that legal challenges are based on discrimination claims, payers would appear to be on the most solid legal ground by refusing to cover assisted reproduction for anyone; “all or nothing” arguments may be worse policy (since they do not allow the ability to

adjust to differences among people), but they appear to be easier to defend against charges of discrimination.

**4. How do you define what is “medically necessary” or “medically required”? How would this relate to the services that were suggested for delisting by the JRP.**

As noted in Chapter 1, section 7.2 (*Canada Health Act*), comprehensiveness, as defined by the *Canada Health Act*, defined insured services in terms of where (in hospitals) and by whom (physicians) they are delivered. However, decisions about what services should be covered for which individuals have been made with providers. Deciding which physician services should be included in the Ontario Health Insurance Plan (OHIP) Schedule of Benefits, and what the fee should be, has been made by MOHLTC in partnership with the Ontario Medical Association (OMA); indeed, the Ontario government even gave the OMA the power to approve any deletions, alterations or additions to the OHIP schedule.

As noted in Chapter 1, section 5.9 (Insurance, Elasticity and Moral Hazard), there is considerable dispute about how to finance health care, with one issue relating to the concept of “need”. One reason that the concept of need has become controversial is that it carries with it, almost by definition, a presumption that needs should be met. This has several implications. First, a need can quickly become a “right”. Second, needs are externally defined (usually by experts), which presumes that one individual knows what another person requires more than they themselves do. Third, because technological innovation is exploding, the “boundaries of what is possible” are also expanding, which soon becomes a question of how much benefit can be gained from carrying out a procedure, and whether it is worth spending resources on (see Chapter 1, section 8.1, Economic Analysis). As a result, determining what is necessary or needed may become a subjective exercise.

Examination of the procedures suggested for delisting by the JRP reveals that many of these dealt with cosmetic procedures, and/or with issues of sexual health and reproduction. (Notably, those recommendations affecting male sexual performance tended to be retained as insured services.) One analysis of the issues surrounding the JRP process and the de-listing of IVF services in Ontario noted the difficulty of de-insuring individual services without taking into account the possible interactions with other parts of the health care system. That analysis noted differences among stakeholders in what they believed constituted evidence, and the possible implications for the legitimacy of the decisions made. It further noted that an additional complexity relating to IVF was that it was not listed in the OHIP Schedule of Benefits as a distinct service with an identified billing code, but comprised a number of procedures, including diagnostics, surgery, laboratory services and medications, some of which might be deemed insured services, and others which might not (Giacomini, et al., 2000).

As noted in Chapter 1, sections 3.4 (Framing) and 4.3 (Scope of Conflict), the manner in which issues are framed may help set the stage for the outcomes of various policy decisions, including determining where, and by whom, the decisions are made. In the case of IVF, de-listing could be framed in terms of re-distributive policy (e.g., in order to achieve cost savings, some services will have to be removed) and/or of regulatory policy (e.g., publicly insured IVF will only be available to patients with a particular diagnosis) and/or of rights. In addition, depending on whether the decisions are made by providers, by regulators, and/or by courts, there are likely to be differences in who is at the table, and what rules are being used.

There are a number of ways of allocating resources (see also Chapter 1, sections 3.6.3, Resource Allocation/Rationing, and 3.6.4, Distributive Justice). The class may wish to discuss



whether these decisions should be based on markets (where individuals decide whether they wish to purchase a good or service) or use “political” approaches that require societal decisions. Mixed models are also possible (e.g., public payment for some, markets for others). Some of the underlying principles are described in Chapter 1, section 3.6 (Ethical Frameworks). For example, the National Institute for Health and Clinical Excellence (NICE) in the UK has published a set of principles on Social Value Judgements. It began with the four principles of bioethics codified in the Belmont Principles: respect for autonomy, non-maleficence, beneficence, and distributive justice, and also noted the importance of procedural justice (see Chapter 1, section 3.6.1, Accountability for Reasonableness). It then added several principles related to evidence-based decision making, including the strength of the evidence, the extent to which it is likely to benefit patients, cost-effectiveness, and individual choice. It explicitly rejected the *rule of rescue*, on the grounds that giving priority to identifiable individuals would not be fair to present and future patients who were not yet identifiable. It also discussed the extent to which decisions might have adverse impacts on vulnerable populations, and the implications for “reducing health inequalities including those associated with sex, age, race, disability and socioeconomic status” (National Institute for Health and Clinical Excellence, 2008).

This tension between the needs of an individual patient and the wider population presents problems for policy makers. One possible strategy is to adopt a list approach (where services are or are not covered). Another is to use a case-by-case approach (which allows decisions to be tailored to individuals). Note that these different strategies have different strengths and weaknesses, and different winners and losers; neither is ideal.

A number of approaches have been suggested to help decide which services should be funded. One approach proposed by Ross and Deber used a *four-screen model*. It applies the following screens sequentially, such that procedures not passing an earlier screen are no longer considered for funding:

*Pre-Screen:* Is the service ethically acceptable? If not, stop. (Note that this can be somewhat difficult to enforce if people seek the service in other jurisdictions with different views about whether the service is ethically acceptable).

*Screen 1: Effectiveness.* Does it work? The decisions for this screen are made by experts, on the basis of evidence. One important distinction is between services that have been proven ineffective and those that have not yet been proven effective. Other issues relate to the burden of proof, and the quality of evidence. Services can be given a “conditional pass” contingent on the need for better evidence (e.g., require such services to be provided only within the context of an evaluation of their effectiveness).

*Screen 2: Appropriateness.* Is it needed? This screen relates to the expected benefit for an individual, given his/her clinical situation. It is also expert-based, and requires evidence, but recognizes some inherent difficulties in determining what cut-off points should be used to decide where the anticipated benefit is deemed to be high enough. This screen is also more susceptible to gaming. Again, conditional passes are possible.

*Screen 3: Informed Choice.* Is it wanted? This screen is value-based; ideally, this judgment should be made by an informed patient, on the basis of his/her preferences.

*Screen 4: Public Provision.* Should the public pay? This screen is also value-based, and relies on public views about what services should or should not be publicly paid for.

One implication of this model is that services that do not pass the first three screens should not be paid for by anyone. “Medically necessary” services would then be defined as services that are seen as sufficiently effective and appropriate that society is unwilling to deny

them to someone on the basis that that person could not afford them. Passing the fourth screen, however, may involve incorporating a series of criteria, including considerations of cost effectiveness and perceived necessity (Deber et al., 1999).

As noted in Chapter 1, section 8.1 (Economic Analysis), assessing the *cost effectiveness* of any therapy requires examining both the outcomes (effectiveness) and costs, compared to alternative courses of action. Outcomes can include considerations of safety; costs can include both direct and indirect costs. Economic analysis also requires comparison of two or more alternatives. In the case of IVF, one common comparator is IUI (see Appendix B of the case), which Ontario does fund.

The JRP had based its decision on the lack of evidence for the *effectiveness* of IVF treatment for any diagnosis other than bilaterally blocked fallopian tubes, but noted that this judgment would be subject to change if new research and/or new technology would show evidence of improved effectiveness. The Royal Commission had undertaken the assessment of efficacy of IVF by evaluating all published trials of the procedure that met certain criteria and supplemented their findings with those of the Canadian Infertility Therapy Evaluation Study, the largest study ever conducted at that time on infertility treatments in Canada. As noted in the case, as of 1993, IVF had been found to be effective only for bilateral fallopian tube blockage; for other conditions such as ovulation disorders, endometriosis, male infertility and unexplained infertility, the study had found a need for more rigorous research (Canada Royal Commission on New Reproductive Technologies, 1993). Since then, the effectiveness of IVF had increased. While the Royal Commission had estimated the live birth rate for IVF to be between 12 to 18%, later data had estimated the birth rate for IVF to have risen to be closer to 30%.

Evidence-based medicine is increasingly being used to support decisions involving limited resources. However, various stakeholders hold differing views on what constitutes relevant and good quality evidence. As noted above, an additional complication is that lack of evidence proving effectiveness is not the same as evidence that the procedure is ineffective; one policy problem is where the burden of proof lies, and what to do until good enough evidence is available.

In terms of *safety*, there was little evidence on the long-term health consequences for children who were conceived through IVF. However, given the association with older maternal age and multiple births, those children might be at higher risk for long-term health consequences, and developmental delays. Women who use assisted reproduction may also face risks. For example, fertility drugs may increase risk of ovarian cyst formation, and egg retrieval is sometimes associated with infection or bleeding.

Because IVF was largely delivered in private clinics and fell outside the definition of insured services, *costs* varied, although some noted that Ontario was extending public payment to cover surgery to repair tubal occlusion. Appendix C of the case gave some estimates of average costs; since multiple cycles may be required before a woman becomes pregnant, these costs could soon add up and become relatively large (Ovo Consulting, 2009).

There are also indirect costs associated with assisted reproduction, largely related to the significant increase in multiple births from certain approaches. Women with multi-fetal pregnancies were 3-7 times more likely to have complications, including hypertension, gestational diabetes, anemia and post-partum hemorrhage. The greatest risk for these babies was risk of prematurity and low birth weight; one study estimated that over 50% of twins and 90% of triplets were born prematurely (<37 weeks gestation) and had a low birth weight (<2,500 grams), compared to only 7% of single-gestation babies. Even after adjusting for degree of prematurity,

multiples were more often admitted to the neonatal intensive care unit (NICU) and required longer stays than singleton babies (Canadian Institute for Health Information, 2006).

As discussed in the case, studies of the cost effectiveness of IVF have largely yielded conflicting results, and the issue remains inconclusive. Note that effectiveness requires looking at the incremental costs and consequences of one alternative as compared to another. Some reports, including *Raising Expectations* by the Ontario Expert Panel on Infertility, assumed that the comparator of SET-IVF should be IVF with multiple embryos implanted; this comparison concluded that SET-IVF was cost effective because it avoided the high cost of multiple births (Expert Panel on Infertility and Adoption, 2009). Other studies, including a 2006 Ontario based economic analysis, have used IUI as their comparison; these found that IUI was more cost-effective, even after accounting for costs associated with multiple births, because several expensive SET-IVF cycles were usually needed to achieve the same birth rate as IUI. Comparing assisted reproduction to doing nothing would require assigning a value to being able to have a child.

Another issue is the time frame to be used for these comparisons. For example, should studies include long-term costs of supporting children born with sequelae of prematurity such as cerebral palsy, or the long-term costs of other neurological or developmental, cognitive, visual, and respiratory impairments in these children? If so, how should the joy that children may bring be valued?

**5. Who should be involved in making the decision about whether IVF should be funded? How should these decisions be made, and how should they be revisited?**

As noted in Chapter 1, section 4.1 (Concentrated/diffuse interests), “public” involvement can mean different things. Examining the JRP process might suggest that there was a high level of public interest, as indicated by the volume and content of input the panel received. The panel heard a broad spectrum of views, from both organized interest groups and individuals. Many individuals offered personal stories of how they had benefited from the services/procedures that were under review. On the other hand, the general public was not really involved. One possible reason was the relatively short time frame between announcement of the hearings, and the hearings themselves (which limited the ability to prepare briefs or receive background material). There was only one day of public hearings, which were held in Toronto, and groups and individuals who wanted to present to the panel had to travel there at their own expense. Another possible reason was that those with concentrated interests would be far more likely to participate.

There is heated debate about the public’s role in the policy making process. Some commentators question whether the public truly influences the process or are simply used to legitimize it. There are debates about what constitutes useful participation, when it is cosmetic, and when it has an impact on decisions, and the extent to which “the public” should involve those who wish to use particular services (concentrated interests), or the public more generally (Aronson, 1993). As noted in Chapter 1 section 4.3 (Scope of Conflict), those individuals or interest groups with significant interest in the outcomes are more likely to participate. As Kellow has argued, “it is the participation of those with opposing views which makes the use of coercion by governments necessary to resolve policy issues; individuals and groups do not participate in politics according to whether they are likely to be coerced, or how that coercion will be applied, but according to whether and how their interests are threatened or opportunities are presented by either the status quo or by policy proposals” (Kellow, 1988).

The Canadian Health Services Research Foundation (Canadian Health Services Research Foundation, 2009) has argued that the experiences, opinions, and preferences of patients, the general public and interest groups play a valuable role in developing high-quality, evidence-based policy especially when difficult, value-laden judgments must be made. Public involvement is defended both on the grounds that it is democratic, and on pragmatic grounds that it is the best way to gain insight into values and priorities, and to build public trust. Flood et al. have noted the variety of processes being used in Canada, and argued that there is a relatively small space for public involvement (Flood, 2006). Chafe et al. argue that meaningful public participation is only possible when dealing with questions or issues for which an organization has viable options, and when there is two-way communication between the public and the decision-maker. They suggest that organizations must consider the degree of influence that participants in the process will have on the final decision; for meaningful participation to occur public input should be given serious consideration in the decision-making process and/or be the deciding factor. They conclude that public input appears to be most useful in obtaining advice on how decisions should be made, and about meso-level decisions concerning the allocation of funds across service levels (Chafe et al., 2008).

One strategy for engaging the public in health policy decision-making is the use of deliberative processes to encourage informed public dialogue and lead to policy recommendations that incorporate multiple points of view (Abelson et al., 2003). The deliberative approach is a collective problem-solving process that involves bringing together a group of people (usually including patients and the general public) with different perspectives on a topic so that they can weigh evidence on a specific issue and debate options, with the goal of collectively developing formal concrete recommendations to help inform decision making (Canadian Health Services Research Foundation, 2009). It can be useful, but also can present similar problems in terms of who is most likely to participate, and how much they really reflect the views of the public.

#### **6. Discuss the role of interest groups in this case.**

As noted above and in the case, different interest groups often *frame* the topic of infertility differently. For example, *religious groups* may argue that IVF is “playing God” and separating sex from reproduction. During IVF, several embryos are created but only some are transferred to the mother. If the additional embryos are disposed of, some claim that this is equivalent to abortion, and is ethically unjustifiable. *Feminist* arguments against IVF may include the following: 1) The infertility industry operates on the assumption that a child is worth having at any cost (financial and health risks). This assumption glorifies motherhood to the detriment of other roles that women have fought hard to achieve; 2) By considering IVF as “medically necessary”, we are strengthening the imperative to have children; 3) Women may be exposed to serious health hazards with hormone therapy; 4) The promotion of IVF is motivated strongly by the needs of a “patriarchal” genetic research agenda; and/or 5) IVF promotes the commoditization of reproduction, women’s bodies and human life (e.g. donor eggs, gestational carriers). However, feminist arguments can also favour IVF (e.g., noting that IVF can empower women to focus on their careers and have families later in life without worrying about reduced fertility as they age).

*Pharmaceutical companies* who sell medication used in conjunction with fertility treatment have supported public funding for IVF. The *medical profession* has not been particularly active in this debate. Some have suggested that this may be because of high profits in

the privately funded market for those providing fertility services. *Researchers* have some interests in this area, particularly given the increasing demand for ova and embryos for research purposes as a result of recent advances in stem cell research for possible tissue transplantation. If funding IVF would increase the number of IVF cycles that are performed in Ontario, then with each cycle, there could be left over embryos that are often donated to research.

Patients with *other medical conditions* may argue that tax money could be better spent elsewhere (particularly for their particular health problems). Advocacy groups for *adoption* have argued that couples who desperately want a baby should adopt a child, suggesting that each year in Canada, 30,000 to 40,000 children in care are legally available for adoption, while on average only 2,300 are adopted. They add that these children could benefit from having permanent families. *Infertility advocacy groups*, including the Infertility Awareness Association of Canada (IAAC) and the Canadian Fertility and Andrology Society (CFAS), have argued that infertility is a medical disease, and that denying clinically appropriate medical care goes against the *CHA*. The “*socially*” *infertile* are defined as same-sex couples, or single women or men; they may argue that they should also be eligible for publicly paid IVF, since they may also wish to have children. As noted above, whose views prevail may vary, and are often related to the relative power of the different groups, as well as to where (and by whom) the decisions are made.

### See also in Chapter 1:

- 2.2.1 Federalism in Canada
- 2.2.2 Charter of Rights and Freedoms
- 3.4 Framing
- 3.6 Ethical Frameworks
- 3.6.1 Accountability for Reasonableness
- 3.6.3 Resource Allocation/Rationing
- 3.6.4 Distributive Justice
- 4.1 Concentrated/Diffuse Interests
- 4.3 Scope of Conflict
- 5.2.1 Regulation
- 5.9 Insurance, Elasticity and Moral Hazard
- 6.2 Payment Mechanisms and Incentives
- 6.4 Professionalism
- 7.2 *Canada Health Act*
- 8.1 Economic Analysis: Cost-effectiveness

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**The following websites may also be useful:**

- Canadian Agency for Drugs and Technologies in Health (CADTH)  
<http://cadth.ca/en/products/environmental-scanning/health-technology-update/issue-10-september-2008/assisted-reproductive>
- Canadian Fertility and Andrology Society  
<http://www.cfas.ca/>
- Health Canada. Assisted Human Reproduction

<http://www.hc-sc.gc.ca/dhp-mps/brgtherap/legislation/reprod/index-eng.php>  
Infertility Awareness Association of Canada  
<http://www.iaac.ca/en>  
Ontario Ministry of Health and Long-Term Care, Medical Advisory Secretariat,  
In vitro fertilization and multiple pregnancies (2006).  
[http://www.health.gov.on.ca/english/providers/program/mas/tech/reviews/pdf/rev\\_ivf\\_101906.pdf](http://www.health.gov.on.ca/english/providers/program/mas/tech/reviews/pdf/rev_ivf_101906.pdf) and the resulting recommendation:  
[http://www.health.gov.on.ca/english/providers/program/ohtac/tech/recommend/rec\\_ivf\\_101906.pdf](http://www.health.gov.on.ca/english/providers/program/ohtac/tech/recommend/rec_ivf_101906.pdf)  
Society of Obstetricians and Gynaecologists of Canada (SOGC) Clinical practice guidelines  
<http://sogc.org/clinical-practice-guidelines/>



## **Chapter 15: Teaching Notes**

### **Prescription for Conflict**

*Bev Lever, Laura Esmail, Linda Gail Young, and Raisa B. Deber*

Note that this case study may also be addressed through a role play exercise.

#### **Outcome**

At the time of writing, Canada had not yet formally responded to the EU demands on drug patents. According to a Canadian Press report, a study by Industry Canada and Health Canada had estimated that these proposals would extend a typical drug patent by 2.66 years, and increase drug costs in Canada by between \$798 million and \$1.95 billion per year. The generic drug industry estimated the costs to be even higher (about \$3 billion per year). Several provincial governments had asked the federal government to compensate them for increased drug costs resulting from any new trade deals (The Canadian Press, 2012). Despite arguments that a national pharmacare program could save billions of dollars, the federal government has not indicated any interest in pursuing a policy issue that it has indicated that it views as a provincial responsibility.

#### **Possible Points for Discussion:**

##### ***1. What policy options should you consider? How would each address such issues as return on investment; international trade policy; and affordability of drug prices?***

Note that the policy options can be categorized in a number of different ways.

The World Intellectual Property Organization defines intellectual property (IP) as “creations of the mind: inventions, literary and artistic works, and symbols, names, images, and designs used in commerce” and a patent as “an exclusive right granted for an invention, which is a product or a process that provides a new way of doing something, or offers a new technical solution to a problem” (World Intellectual Property Organization, 2012).

How should we determine what should and should not be patentable? Canadian patent law allows broad interpretation for what is “new and inventive”, making it easier for inventors to manipulate the patent system. Recently, the brand name companies have been accused of abusing the Canadian patent system, through a method loosely termed “evergreening”; this involves minor modifications to a pharmaceutical product with the goal of extending the patent life of the drug. Another contentious issue involves whether new patents should be issued for finding new uses for existing medications.

The exclusive marketing rights granted to owners of a patent result in a monopoly for the term of that patent. This enables the companies to charge higher prices, which are intended to allow them to recoup the costs of research and development, complying with regulations, as well as marketing and producing the product. This policy can be defended; clearly, not all of those costs are incurred by generic drug companies. However, there is considerable dispute about how much it actually costs brand name companies to produce one new pharmaceutical product (Angell, 2004; Goozner, 2004; Lexchin, 2004).

Intellectual property provides incentive for companies to develop new treatments or improve existing ones but it also raises drug prices and prevents people from accessing

treatment. Where should the line be drawn between protecting intellectual property and protecting the health of the public? When countries such as India or Brazil issue compulsory licensing on an anti-retroviral drug to allow more low-income people to receive treatment, should this be seen as good (improving public health) or bad (stealing intellectual property)?

Another issue is the extent to which jurisdictions are constrained in their potential policies by international bodies. This may involve the setting and enforcement of rules by such bodies as the World Trade Organization (WTO), and/or other restrictions on national sovereignty. Enforcing such rules, however, is not always simple. One clear example is the effort to set and enforce international standards for environmental protection. International agreements may provide multinational corporations with extreme mobility and minimal accountability. At one extreme, *globalization* makes it easier for corporations to search the globe to locate the cheapest raw materials, the lowest wages and the most lucrative investment opportunities. The result can be a race to the bottom. At the other, globalization can help ensure that nations comply with international standards, and increase the well being of their populations (see also Chapter 1, section 5.5, Globalization).

The brand name industry claims that high drug prices are needed to fund R&D. A host of ethical and policy dilemmas result, particularly since Canada represents a small portion of the world's pharmaceutical market, and does not have a large share of pharmaceutical R&D. To what extent is cross-subsidization ethical? For example, should Canada pay higher drug prices to fund R&D for diseases common to developing countries?

*Return on investment* is the point at which an investment pays for itself in value received. The question of how much patent protection is appropriate is an ongoing policy dilemma. How much return should brand name companies receive to recover the sunk costs of drug discovery and development? What counts as R&D as opposed to as marketing and advertising? How are the benefits assessed?

A related concept is that of *free riding* (see Chapter 1, section 3.5, Public Goods and Externalities). A purely rational individual has an incentive to avoid paying for public goods. Although these arguments are raised frequently, it should be noted that most innovations in drug therapy do not, strictly speaking, qualify as public goods, since the benefits can be restricted to those willing to pay for them. (Innovations affecting infectious diseases may be an exception, since the public may indeed benefit from herd immunity.) However, the pharmaceutical companies have claimed that not all research generates usable products, and that prices therefore must be high enough to allow all of their research and development costs (including those for unsuccessful products) to be recouped. They have argued that restricting prices can mean that countries that do not subsidize innovation benefit from those that do. A related question is whether compulsory licensure allows generic drug companies to be free riders, making profits without investing in research. Others note that much of the basic research has been done in universities, and paid for by governments, rather than by the pharmaceutical companies. There are no clear answers, but the class may wish to note the implications of different ways of framing this issue and deciding what is "fair".

## ***2. Discuss framing and how this affected the debate.***

Note that the Canadian government successfully framed the debate as a national question of intellectual property and the appropriate trade offs between economic benefits to Canada and international trade pressures. Had it been decided in an international arena, the scope of conflict

(see Chapter 1, section 4.3) might have widened to involve other countries, the international media, NGOs, advocacy groups, etc. and been harder to control.

A policy issue can be framed in a number of different ways, each of which leads to a different policy analysis (see Chapter 1, section 3.4, Framing). The frame can be crucial for the policy's acceptance or rejection. Minister Michael Wilson used a trade-based frame, emphasizing the benefits of being on a level playing field with other countries (in respect to regulation) and the amount of research and development that might result for Canada. He downplayed the increase in drug costs and ignored the distributional impacts of who would pay, and who might benefit. Brand name companies framed the issue as providing a fair environment for intellectual property protection, which might result in more R&D investment and more jobs, as well as the benefits of drug discovery to the common public good. Generic drug companies framed the bill as an issue of drug affordability, also emphasizing the detrimental impact Bill C-91 would have on the generic drug industry and employment. Patients (particularly seniors) emphasized the negative aspects of the bill, saying that the burden of higher drug costs would fall mainly on their shoulders. Had these latter issues been highlighted in the debate, the chances for policy adoption would have likely decreased. Despite Minister Wilson's efforts to portray Bill C-91 as having minimal negative consequences and tremendous benefits, the media didn't always agree; some stories portrayed Bill C-91 as having long-term disastrous effects on drug costs. Had the Ministry of Health led the debate, the policy issues being discussed might have been different, emphasizing access to pharmaceuticals, health services and sustainability of Canada's "universal" health care.

### ***3. Discuss the positions of the key stakeholders.***

As noted in chapter 1, section 4.1 (Concentrated/Diffuse Interests), interests can be classified as either concentrated or diffuse. In this case, industry had concentrated interests, as did those patients reliant on their products. Taxpayers and holders of insurance policies had more diffuse interests, and were less likely to participate in the policy process surrounding patent protection. There were also differences in the resources available to the various pressure groups (see Chapter 1, section 4, Interests), and hence in their ability to influence policy. Those concentrated interests likely to be strongly affected by these policies (including the brand name and generic drug manufacturers) have a strong incentive to communicate with decision-makers and be aware of pending policy initiatives. Note that the legislative hearings mobilized the policy community (see Chapter 1, section 4.2, Policy Communities), with the brand and generic industries, hospitals, physicians, pharmacists, seniors, payers, and governments all testifying.

### ***4. Discuss scope of conflict. Where might these questions be dealt with? How might that affect which issues were raised, and the powers of different stakeholder groups?***

As Chapter 1, section 4.3 (Scope of conflict) notes, these different policy debates will involve different stakeholders, often operating under different rules.

*International trade policy* questions operate to some degree under international rules, and involve the extent to which the national government wishes to ensure trade harmonization. Note that there may be difficulty in enforcing the resulting rules. For example, charges of unfair trade practices have been made for a series of industries, including steel, wood products, beer, and food products. In the case of pharmaceuticals, note the influence of such trade agreements as the North American Free Trade Agreement (NAFTA), and the Trade-Related Aspects of Intellectual Property Rights Agreement (TRIPS) provisions of the GATT negotiations. Indeed, these

agreements led to several complaints filed against Canada under the WTO Dispute Resolution mechanism, by the European Union, and by the United States. Canada lost both, and had to amend its patent provisions to delay the entry of generic drugs and extend patent provision; the cost to Canada was estimated at over \$40 million.

In contrast, if the debate is one about *economic policy*, the stress may be on the ability to protect domestic industries (which can conflict with the imperatives of trade policy). Also, to the extent that industries are located within particular jurisdictions, there may be conflict within a country. In the case of pharmaceuticals, most of the research jobs were located in Quebec at that time, whereas the costs were incurred across the country.

If the debate is treated as concerning *innovation policy*, the focus may be on patient groups wishing better treatments for particular conditions, and on those wishing to have more job creation. If the debate is framed as being about *health policy*, more attention may be paid to ensuring that pharmaceutical products are available at an affordable cost.

Note that there are differences across Canada in who pays for which pharmaceuticals for whom. Who bears the burden of increased drug costs varies accordingly. While drug plan eligibility criteria vary across the provinces, it is mainly the elderly, disabled and social assistance recipients who are the beneficiaries. One might debate whether it is more equitable to limit the number of people who can receive benefits, limit the benefits available, and/or implement a deductible or user pay system to fund the drug plan. Other questions might include how a payer should decide what drugs are worthy of coverage, the roles that evidence and cost-effectiveness should have (and how it differs for richer and poorer jurisdictions), and whether payers should cover experimental drugs, “lifestyle” drugs or “me-too” drugs (see also Chapter 12, *At Any Price*). There are no simple answers, and decisions are likely to vary across jurisdictions.

### See also in Chapter 1:

- 3.4 Framing
- 3.5 Public Goods and Externalities
- 4. Interests
- 4.1 Concentrated/Diffuse Interests
- 4.2 Policy Communities
- 4.3 Scope of Conflict
- 5.5 Globalization
- 6.3.2 Sickness Care Subsectors
- 7.2 *Canada Health Act*
- 9.1 Canadian Data

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## **Chapter 16: Teaching Notes**

### **Ask Your Doctor: Direct to Consumer Advertising of Prescription Medicines**

*Chris Bonnett, Christopher J. Longo, Yeesha Poon, and Raisa B. Deber*

#### **Outcome**

The court case was abandoned when CanWest filed for bankruptcy. At the time of writing, changing policies about DTCA was not high on the policy agenda.

#### **Possible Points for Discussion:**

***1. What are your options? Discuss the advantage and disadvantages of each. Discuss regulation as a policy instrument.***

The policy options suggested in the case for Health Canada are unlikely to be universally applicable. The balance of risks and benefits will clearly vary by type of product and type of user. As such, the policy debate is likely to focus on larger issues, including what (if any) role the Canadian government wishes to play, and views about the role of government. Another issue is who will bear the costs of the selected actions. As noted in Chapter 1, section 5.2.1 (Regulation), regulation is a policy instrument that can be used to control behaviour while placing the costs of compliance largely with the organizations/people being regulated. This is often popular with government, but not with those being regulated.

***2. Discuss the various conflicting policy goals, and how these relate to: individual autonomy? The role of the state? How would you balance such issues of freedom of speech, public safety, and costs?***

As noted in Chapter 1, section 3.2 (Role of the State), people have different views as to the extent to which government can infringe individual liberty. DTCA exemplifies an attempt to balance these views. On one side, consumer sovereignty would say that people should be able to buy what they want. If one takes a libertarian view, the state should take a minimal role. For potentially hazardous products, one might agree that an informed consumer needs accurate information, and hence might regulate to ensure “truth in advertising”. However, if someone still wishes to buy such a product, the state should not intervene at all. One description of this model is *caveat emptor* (buyer beware), in which those harmed (or their survivors) are free to sue if things go badly. Products that are potentially hazardous consumer products include not only pharmaceuticals, but also alcohol, automobiles, firearms, as well as sophisticated (albeit non-lethal) financial instruments such as stock and bond investments. On the other side, some argue that the possibility of externalities and adverse consequences justify a stronger state role. Paternalism might justify a government role to protect people from bad decisions. A compromise position might justify state involvement for those not deemed competent to make their own decisions (e.g., children), and/or for situations where others would be affected (e.g., requiring drivers to be licensed on the grounds that untrained drivers might crash into others). Which policy goals should be stressed, and how the trade-offs should be managed, relate to values, rather than to evidence. As noted in Chapter 1, section 3.6 (Ethical Frameworks), several ethical principles could be brought to bear, including *autonomy* (allowing capable persons to make their

own decisions), as well as *non-maleficence* (the duty to do no harm or to minimize harm and risk).

A related question is who should control what? What is the role of government? In most jurisdictions, they are involved with the drug approval process; should they also regulate and/or monitor manufacturing plants to ensure the product is being made safely, and contains the active ingredients? What is the role of: physicians, pharmacists, pharmaceutical companies, patients, and the media? This may also depend on the type of drug (e.g., what conditions it is intended to treat, how safe it is, how much it costs, and the costs and consequences of over-use, under-use, and misuse (Institute of Medicine, 2001).

Over-the-counter (OTC) drugs are clearly commercial products, being available in pharmacies, grocery stores and department or discount stores without a physician's prescription. A sub-category of products, such as those containing codeine, do not require a prescription, but are available only at pharmacies, are kept "behind the counter" rather than on open shelves, and must be specifically requested by the consumer from the pharmacist. Which drugs are so classified vary by province, and by nation. For example, Claritin and Allegra are non-prescription medications in Canada, but are two of the most heavily advertised prescription medicines in the United States. Drug classification also varies over time. For example, in 1998-99, most provinces moved nicotine patches from prescription to OTC status, and similarly reclassified such ulcer medications as ranitidine.

***3. Discuss the role of interests, and the views (and influence) of such stakeholder groups as: pharmaceutical manufacturers (new products, generics), physicians, pharmacists, federal government, provincial governments, private payers, consumers, Pharmaceutical Advertising Advisory Board (PAAB), Advertising Standards Canada (ASC), and media.***

The views of the key actors are discussed in the case. One additional nuance is that the brand-name drug manufacturers are all headquartered outside Canada, typically in Switzerland, Germany, the United Kingdom, or the United States. Canada accounts for only about 2% of the world's prescription drug market. Even when the companies have Canadian offices, they are vulnerable to being closed; indeed, as noted, most of these companies have closed their research operations in Canada.

***4. Discuss how these issues might be framed.***

As noted in Chapter 1, section 3.4 (Framing), how people react to issues depends in large part on how they are depicted. A non-technical explanation of framing theory is that the same set of facts can be manipulated to serve different interests and present different messages. Framing is often controlled by the manner in which the choice problem is presented as well as by norms, habits, and expectancies of the decision maker. As one example, the tobacco industry might frame restrictions on their ability to advertise their products as an infringement on their right to communicate with their customers about a legal product. Others might frame it as efforts to encourage the use of a product that causes extensive death and disability.

In the case of DTCA, several frames were evident. These include:

Manufacturers and media have stressed the role of those who might use pharmaceuticals as competent consumers with a right to obtain information about products that might help them. *Consumer empowerment* is seen positively, and DTCA is presented as one mechanism to help achieve it.



Many health professionals stress *public safety* and the risks of inappropriate prescribing and poor medication compliance. This may focus on certain population groups who are seen to present special problems for such reasons as diversity in abilities, literacy, health status, or multicultural impediments, and hence may be less able to self-manage medications. This frame stresses the significant imbalance in the knowledge base of health professionals and their patients. Related frames relate to who should control prescribing of medication (which could be various combinations of physicians, pharmacists, and/or consumers).

A *cost* frame notes the costs of drugs; this can also be framed in terms of the costs of ill health if valuable products are not available. A related frame may stress who will (or will not) pay physicians and pharmacists for their time to explain about drugs and how to use them.

Another frame looks at *benefits* and who should pay for what. Looking specifically at prescription drugs, one could view them on a continuum, with some aimed at lifestyle or cosmetic problems (e.g., Propecia for male baldness, Accutane for severe acne, Zyban for smoking cessation and Viagra for erectile dysfunction) and others being life saving or life sustaining. In turn, such distinctions might be used to justify different payment policies in terms of which products to put on formularies (lists of covered drugs), as well as how the costs should be shared between insurers (public or private) and those using those drugs.

Another potential issue relates to products for controversial conditions (especially family planning); some consumers have objected to seeing (or having their children see) information about such conditions displayed in public places.

***5. Discuss the role of jurisdictions, particularly given electronic new media. How does this relate to the scope of conflict?***

The *Canada Health Act* (see Chapter 1, section 7.2) requires provinces and territories to fund all medically necessary hospital and physician services, including drugs used in hospitals, but not those administered to out-patients. The federal government is responsible for the safety and efficacy of new medicines through the Therapeutic Products Directorate of Health Canada, and the pricing of new, single-source prescription drugs through the Patented Medicine Prices Review Board. Each province separately evaluates all federally-approved drugs and then decides which meet its own coverage criteria. For example, Ontario's *Transparent Drug System for Patients Act* was introduced with the goal of delivering better "value for money" in various ways, including more rapid review for all drugs, whether brand name or generic products. Provincial drug budgets have rapidly increased over the last decade due to growth in covered population, changes in treatment patterns (less hospitalization), new product introductions, and changes in the mix of products. From a policy standpoint, the task force would be faced with ambiguity in terms of what role the federal government should play, what should be done by national bodies (i.e., reflecting informal collaboration among the provinces/territories), and what by other stakeholders.

As noted in Chapter 1, section 4.3 (Scope of Conflict), the outcomes of policy debates may vary, depending on who makes the decisions, under what rules, and who is at the table. If DTCA is seen as a "truth in advertising" matter, the results may be different than if it is seen as a drug policy question, or as a question of media policy, or as one of international trade.

Globalization (see Chapter 1, section 5.5) also challenges the ability of individual jurisdictions to control policy. The internet provides a clear example; if one jurisdiction permits certain activities, it is difficult for other jurisdictions to block that information. This means that no one owns or effectively controls internet information. Patent and trade-mark infringements

can be pursued through the courts, but this is especially difficult when multi-national companies are involved and must protect their intellectual property around the world under different legal systems. An added complication with the internet is that someone must actually discover that an infringement exists.

The number of websites with health information (or misinformation) has exploded over the years; with the help of Google, consumers can easily find information on the Web about any treatment. In addition, information is available through social media (e.g. Facebook, Twitter). However, such information may not have been medically reviewed, and may or may not be accurate. Another complication is determining who is sponsoring websites. As one example, the Arthritis Society of Canada has obtained funds from a number of pharmaceutical companies and notes this prominently on its website. As noted in Chapter 1, section 4 (Interests), the term “astroturf” is sometimes applied to organizations that may appear to be grassroots, but are seen to be controlled by other interests (Lyon & Maxwell, 2004), although the groups themselves might argue that the ties are mutually beneficial.

In addition to advertising, the class may wish to note another largely unregulated area, whereby drugs manufactured in one jurisdiction can be ordered in other jurisdictions through the internet. In addition to issues of whether a physician has prescribed that product, there have also been quality control issues, including selling counterfeit drugs lacking the active ingredient.

Another challenge is the interplay between industrial and health policy, especially in Ontario and Quebec where the brand-name and generic industries had their headquarters and research facilities. These jurisdictions clearly wished to encourage pharmaceutical research as a source of excellent jobs, although, as noted, the industry has instead been retrenching and closing most of their Canadian research facilities. The brand-name and generic industries have argued about their own and each other’s net impact on provincial economies; neither have ministries of health and industry collaborated well to determine the net value of economic benefits vs. additional health care costs.

### See also in Chapter 1:

- 2.2.2 Charter of Rights and Freedoms
- 3.2 Role of the State
- 3.4 Framing
- 3.6 Ethical Frameworks
- 4 Interests
- 4.3 Scope of Conflict
- 5.2.1 Regulation
- 5.5 Globalization
- 5.9 Insurance, Elasticity and Moral Hazard
- 6.2 Payment Mechanisms and Incentives
- 6.3.2 Sickness Care Subsectors
- 7.2 *Canada Health Act*
- 9.1 Canadian Data

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**The following website might also be useful:**

Health Canada: Drugs and Health Products Policies and Guidance Documents  
<http://www.hc-sc.gc.ca/dhp-mps/advert-publicit/pol/index-eng.php> .

## **Chapter 17: Teaching Notes**

### **Rehabilitating Auto Insurance**

*Paul Holyoke, Marie Balitbit, Lee Tasker, Raisa B. Deber*

#### **Outcome**

As noted in the case, there were a series of changes affecting processes, fees paid to providers, and premiums. Claims continued to rise. At the time of writing, yet another set of potential modifications to auto insurance policy were under debate. Trade-offs were complex. On the one hand, the Ontario Automobile Insurance Anti-Fraud Task Force concluded that fraud was substantial, and was having a major effect on premiums. On the other, there were concerns that legitimate claimants were having to wait too long for care, and that many requests for treatment were being denied. One interesting complexity was the requirement that claimants could not go to court to enforce no-fault accident benefits until mediation had been sought and had failed. The Financial Services Commission of Ontario (FSCO) was responsible for mediation, and had rules stating this must be completed within 60 days of filing an application. However, they decided that the 60 day period would start only after FSCO had appointed a mediator; the backlog was sufficient that this might take 10-12 months after a request was filed.

#### **Possible Points for Discussion:**

***1. Why is the government obliged to do anything at all? What interest generally should the state have in insurance? How does this relate to ideas about the role of the state?***

As noted in the case, auto insurance premiums frequently became a matter of public concern, and often an election issue. One reason for government involvement is as a response to this public concern.

Another reason relates to externalities (see Chapter 1, section 3.5, Public Goods and Externalities). This gets into views about who should pay the costs of accidents (see Chapter 1, section 3.2, Role of the State). There are various models of welfare states, which in turn have different implications for who should pay for what. At one extreme, one could argue that government has an obligation to ensure that all of its citizens have a reasonable standard of life. At the other, one might argue that individuals should be responsible for themselves. Most would agree, however, that if someone is harmed through no fault of their own, they should not be expected to pay all of the resulting costs. At minimum, this would be an argument for ensuring that those putting others at potential risk are in a position to assume the costs of damages they cause. In turn, this would argue for either only allowing the wealthy to drive, or for requiring risks to be pooled through insurance (see Chapter 1, section 5.9, and Appendix A to the case).

In turn, this might call for a public role in ensuring and regulating the insurance market. From this perspective, the purposes of state intervention in auto insurance may include various combinations of the need to: ensure the insurance market works well; make sure people can get insurance so they can drive; make sure people can get insurance at an affordable rate; protect consumers by promoting marketing integrity; ensure consumers have insurance benefits when they need them by ensuring the solvency of insurers; provide a fair dispute resolution mechanism; and/or make sure the government is not responsible for the costs of car accidents.

**2. Does the state's interest and role in insurance vary with different types of insurance (e.g., health care, property damage, income replacement)?**

As noted in the case, Ontario policy was to require some, but not all, kinds of coverage. Coverage for health care (for the claimant and other parties) was mandatory, as was coverage for property damage to others. This policy helped ensure that the person inflicting the damage, and/or his/her insurer, rather than the government, should bear the financial consequences. However, it did not require insurance against property damage to the individual's own vehicle unless they were not at fault. Many of the tweaks to the insurance market related to the level of coverage required (and whether injuries had to be beyond a particular cut-off), to whether there should be ceilings on liability, and to whether it was appropriate to compensate regardless of fault. (One argument could be that determination of fault was often expensive and time consuming, and that no-fault compensation was often more cost-efficient.)

**3. Discuss the consequences of competition in an insurance market. Are there natural monopolies? What is the role of community rating? What is the role of the Take All Comers rule? What would the likely consequences of a fully competitive free market in insurance be?**

It is a well-known feature of insurance that community rating (charging everyone the same premium) is inherently unstable if there is competition (more than one insurer) and if at least one competing insurer rates on risk (has different rates for persons of different risk levels). Under those circumstances, it is economically advantageous for the low-risk individuals to move to the risk-rating insurer because that insurer can offer them lower premiums in recognition of their lower risk of incurring damages. Since the high risk individuals remain with the community-rating insurer, its costs (and rates) will increase. In what is often called the *premium death spiral*, the community-rating insurer's rates would then go up, and more and more individuals would leave the community-rating insurer (Fein, 2001). One key issue is whether society finds it acceptable that some people will not be insurable (or will be insurable only at a very high rate), or whether they wish to have the lower-risk individuals cross-subsidize those at higher risk.

This is likely to vary by type of insurance. Society may wish to ensure that everyone can get health insurance, rather than implement a model designed to ensure that the costs of someone with a history of cancer should not be born by those who are healthy (see also Chapter 18, Everybody Out of the Pool). But society may also find it appropriate that those with a poor driving record should no longer drive. Deciding which factors are legitimate bases for segmenting the population is another political issue. For example, if the young in general have more accidents, does this mean that a young person who is a good driver should nonetheless pay higher rates? The Ontario policy did specify that certain grounds should not be used to risk rate, while allowing others.

Another issue is whether the state should help set premiums, or allow them to be set by insurers. Note that if there are many insurers, with no dominant players (as is the case in the Ontario auto insurance market), one could argue that competition could be allowed to help reduce premiums. However, the ability of insurers to negotiate with customers and with service providers (and therefore have some greater level of control and predictability of costs) is also limited in a contested market, particularly if no player is large enough to engage or dominate the overall customer or the service provider (e.g., health care, collision repair, etc.) communities. This absence of market power would also make it harder to deal with potentially fraudulent claimants.

**4. What policy instruments are available to a government that wants to do something about insurance? Give examples of how the various instruments could be applied in this case.**

As noted in Chapter 1, section 5.2 (Policy/Governing Instruments), there are a number of policy instruments that could be used (Doern & Phidd, 1992). Examples by category of instrument include:

*Do nothing:* Let the market sort itself out, which could mean that some people will be left uninsurable or insurable only at extremely high cost;

*Exhortation:* Ask the insurance companies to reduce their rates, ask people to report potentially fraudulent behaviour they observe, and/or make more consumer information available;

*Expenditures:* Government could take on more medical costs through OHIP (e.g., rehab, pharmaceuticals), and/or could directly subsidize premiums for high-risk drivers;

*Taxation:* Give a tax deduction for auto insurance premiums, and/or give a targeted deduction for selected drivers (e.g., those in rural communities);

*Regulation:* Change the auto insurance product by reducing benefits or restricting entitlements, ask the Law Society to regulate paralegals, draw up collision repair shop standards and enforce them, constrain health professionals' freedom to treat as they see fit (for example, more restrictive pre-approved frameworks), and/or increase fraud detection activities;

*Public ownership:* Make auto insurance public, bearing the financial costs of taking over the business and the political and economic costs of job loss among private insurers if efficiencies of scale reduced the need for employees in the insurance industry.

One key policy instrument that policymakers have used to deal with the auto insurance industry is regulation. Note that the extent of regulation varies by type of insurance. One key factor that affects policy design is the extent, and implications, of moral hazard (see Chapter 1, section 5.9). How often, and under what circumstances, might people "take advantage" of the fact that they are insured against their losses. If an accident victim is otherwise unemployed, there may be an incentive to overstate the degree of disability; insurance against injuries in the workplace presents similar dilemmas. Similarly, providers may have an economic incentive to over service. At the extreme, there have been examples of dubious practices, occasionally fraudulent, among those who repair automobiles, as well as among those providing rehabilitation services. On the other hand, insurers may have an economic incentive to understate the amount of damage and to underservice.

Another factor relates to who is allowed to determine what needs to be done to mitigate damages. For some damages (e.g., property damage), there are relatively objective standards. For example, a car may need body work to bring it back to its pre-accident state. Other damages, particularly health needs, are determined in part by professional judgment. A major protection against fraud and self-interest is professionalism (see Chapter 1, Section 6.4, Professionalism), which assumes that professionals will act honestly and honourably in the best interests of their patients. This may or may not be sufficient.

Another regulatory role that government may play is to help ensure that there is a fair process for adjudicating claims; this may or may not include use of the courts.

**5. How have the various interest groups framed the issue in this case and what options do or might they support?**

There are multiple ways in which this issue can be framed (see Chapter 1, Section 3.4, Framing). In turn, this may affect which policy issues are being debated, and who is involved in deciding them (see Chapter 1, Section 4.3, Scope of Conflict).

Within the Ontario government, the Ministry of Finance has taken the lead. It has framed the issue as one of cost or affordability, and supported cost-cutting to ensure viability of the insurance industry and the availability of insurance to individuals. Note that several other government departments could have become involved, but to date have not. This might include the Ministry of Transportation (particularly with respect to road safety and accident prevention), the Ministry of Health and Long-Term Care (which at the time of writing did not pay for much of the outpatient rehabilitation costs, although it might have to pay for the costs of necessary hospital and physician services, and also had a role in the regulation of health professionals).

The Financial Services Commission of Ontario (FSCO) framed the issue as one of industry viability and the availability of auto insurance, and argued that costs would have to be controlled.

Auto insurers and the Insurance Bureau of Canada (IBC) framed the issue similarly, arguing that industry viability was threatened by excessive costs and fraud, including overuse of health care prescribed by health professionals. The insurers argued for giving them more control to enable cost cutting. Note that this group of concentrated interests have been particularly involved in attempting to influence policy on this issue.

Those providing services, including tow truck drivers and the professional regulatory colleges, have not taken coordinated positions on this issue, although individuals in these groups may have spoken out.

In contrast, some professional associations have become involved, with the Ontario Physiotherapy Association being the most vocal in opposing health care provider fee cuts unless there was input from their professions. Some providers have joined into a group, the Alliance of Community Medical & Rehabilitation Providers, whose web page indicates that they represent “some 80 healthcare organizations and about 3,500 healthcare providers including physiotherapists, occupational therapists, speech language pathologists, chiropractors, psychologists, rehabilitation therapists, social workers, personal support workers, rehabilitation support workers and case managers. It is these individuals who are the primary providers of healthcare and rehabilitative services to Ontarians who are injured in automobile accidents.” In 2012, they noted that 42% of requests for treatment were being rejected by insurers, up from about 11% prior to September 2010.

Lawyers and law firms have tended to frame this as an issue of injured persons’ rights, and argue that such disputes must have the opportunity to be pursued through the courts (or other suitable dispute resolution mechanisms); they often focus on injured persons who would not otherwise get full compensation, and have opposed reducing benefits.

The Consumers’ Association of Canada has framed the issue as one of excessive costs to consumers; they argued that insurers were gouging the public. Note that these different frames are likely to lead to different policies.

### **See also in Chapter 1:**

- 3.2 Role of the State
- 3.4 Framing
- 3.5 Public Goods and Externalities
- 4.3 Scope of Conflict



- 5.2 Policy/Governing Instruments
  - 5.2.1 Regulation
- 5.9 Insurance, Elasticity and Moral Hazard
  - 6.1.1 Public and Private
- 6.3.2 Sickness Care Subsectors
- 6.4 Professionalism
- 7.2 *Canada Health Act*

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### The following websites may also be helpful:

- Insurance Bureau of Canada: Car Insurance: [http://www.ibc.ca/en/Car\\_Insurance/index.asp](http://www.ibc.ca/en/Car_Insurance/index.asp)
- Ontario page: [http://www.ibc.ca/en/Car\\_Insurance/ON/](http://www.ibc.ca/en/Car_Insurance/ON/)
- Alliance of Community Medical & Rehabilitation Providers:  
<http://www.ontariorehaballiance.com/index.php>



## **Chapter 18: Teaching Notes**

### **Everybody Out of the Pool: Financing Health Expenditures through Medical Savings Accounts**

*Kenneth Cheak Kwan Lam, Mark Rovere, and Raisa B. Deber*

#### **Outcome**

At the time of writing, MSAs have not been implemented. Wildrose lost the provincial election in 2012. Although there is a mention of MSAs in the health policy portion on their website, they are given minimal attention, and described in terms of encouraging prevention.

For a fuller discussion of some of the issues related to MSAs, and the accompanying citations, see also the papers by Deber and Lam written for CHSRF (Deber & Lam, 2011a, 2011b). Much of the discussion below was based on those documents.

#### **Points for discussion:**

##### ***1. What sort of good is health care? Discuss the differences between utilization, demand, and need.***

As noted in Chapter 1, section 5.9 (Insurance, Elasticity and Moral Hazard), some theorists argue, on both ethical and empirical grounds, that utilization of health services differs from consumer goods in that it is (or at least should be) based on need rather than demand. These terms can be defined as follows: “In health economics, the term demand is the amount of a good or service consumers are willing and able to buy at varying prices, given constant income and other factors. Demand should be distinguished from utilization (the amount of services actually used) and need (which has a normative connotation and relates to the amount of goods or services which should be consumed based on professional value judgments)” (Academy Health, 2004). The class may wish to discuss the differences among types of services, particularly in the extent to which utilization is related to demand or to need. Examples might include cardiac surgery, cosmetic surgery, primary care visits, naturopathy, etc.

A related issue is who should make the decisions about what care should be used. If health is a consumer good, then patients/customers would be in the best decision to decide what they want. Particularly when moral hazard for consumers is seen to be a major issue, financing models that use price signals would seem optimal to encourage wise purchasing, which in turn requires that patients have enough information to do so. In contrast, if it is assumed that providers make the treatment decisions, ideally on the basis of their professional judgments about what the patient needs, the policy emphasis would focus not on price signals to “consumers,” but on how best to pay providers for their services and the incentives inherent in different approaches to payment (see Chapter 1, section 6.2, Payment Mechanisms and Incentives). As one prominent UK health economist has noted, “if the policy objectives are expenditure containment and greater efficiency in resource utilization, the price mechanism should be used to affect the behavior of the primary demander and the supplier: the physician” (Maynard, 1979). However, to the extent that MSAs can be used for other types of services, the primary demander of care may not necessarily be the physician.

The literature on MSAs reflects these philosophical differences in views about who does, and should, make treatment decisions. One argument repeatedly raised by MSA advocates is the

beneficial implications of encouraging providers to compete for customers; this is sometimes taken as far as urging the abolition of legal and regulatory barriers to people purchasing pharmaceuticals (on-line) without the need for a doctor's prescription, and envisioning physicians competing for customers on the basis of price (Herrick, 2005). Similarly, advocates of Canadian Health Spending Accounts, described briefly in Appendix A of the case, often justify them in terms of consumer choice, since they can be used for a variety of services that would not conventionally be deemed "medically necessary".

A related concept arises from what is known as the "principal agent" problem, referring to situations where one party makes decisions on behalf of another. Clearly, problems can arise if the interests of the agent and the client are not well aligned. To the extent that what is often termed "supplier-induced demand" exists, providers may respond to incentives to supply more (or different) services to maximize their own revenues. Certainly, for health care, this tendency should ideally be minimized by professional norms stressing the importance of meeting needs rather than demands, but badly designed financing programs can introduce perverse incentives. Indeed, the quality improvement movement is attempting to minimize all of the three quality problems identified by the US Institute of Medicine -- overuse, underuse, and misuse (Institute of Medicine, 2001).

Unsurprisingly, clinicians argue that it may not be reasonable to think of patients as savvy consumers, particularly given the complexity of disease, and the emotional issues involved in dealing with serious illness (Callahan, 2008). Concerns have also been expressed about the implications of a consumer-directed model for the physician-patient relationship, the potential to undermine professionalism and trust, as well as issues of legal liability if patients choose badly. Clearly, questions relating to what the roles of patients and providers should be (as opposed to the extent to which providers actually do make treatment decisions) are not based on evidence, but on values. Data does suggest both that, in practice, providers do make most decisions -- particularly those relating to high cost therapies -- and that most patients state that they prefer shared decision making models to models where patients control decision making (Coulter et al., 2008; Deber et al., 1996; Deber et al., 2007).

Regardless of who is paying for care, it is important to recognize that, for services where those consuming health care do not control their own utilization, it is less likely that having MSAs can induce wiser purchasing decisions. The concepts of "need" and "appropriateness" are key. To the extent that care not purchased was not necessary, there is the potential for a "win win" of lower costs and better outcomes. In contrast, where charges to patients result in barriers to seeking needed care, there is the potential for a "lose lose" of worse health outcomes and higher total costs (which may be short-term and/or long term). The balance clearly depends upon the population, the treatment alternatives, and the time frame. There are also equity concerns, particularly if these models widen socioeconomic disparities in care (Bloche, 2006, 2007).

## ***2. Who should pay for what? Does this vary by type of service? How does this relate to views of the role of the state? About resource allocation ethics?***

As seen in Chapter 1, section 3.2 (Role of the State), there can be varied ideas about the extent to which government should be involved. Medical savings accounts are a good fit with libertarian ideas that individuals should decide what care they want to purchase. The role of the state may be to help shelter income and allow such services to be purchased with before tax dollars. Others might ask why, if one adopts a libertarian view, the tax system should be used to

subsidize only some services, rather than cutting overall taxes and allowing individuals to decide what they wish to buy.

Different funding models may thus reflect different views about which costs should be born collectively (Stone, 1993). There is no correct answer. People's preferences can and do vary, both in general, but also depending on the populations being served, and/or the items being covered.

Tables 18.1 and 18.2 in the case provide some data about the distribution of health expenditures across categories of care for 2009. Note that 29.1% of total expenditures went to hospitals, of which only 9.2% came from private sources. However, much of this fell into the non-consumption category. As a result, only 1.7% of hospital spending was paid out-of-pocket (OOP), with this sum accounting for 3.4% of total OOP expenditures. Another 2.4% of hospital spending was paid through private insurance, with this category accounting for 5.8% of total private insurance expenditures.

Those tables clarify that private spending is concentrated on such services as other professionals (including dental care and vision care), and drugs. At one extreme, all over the counter (OTC) drugs and personal health supplies are paid for privately out-of-pocket, and they account for 18.5% of total out-of-pocket spending. Prescribed drugs are more varied; just over half (53.5%) is paid privately, with much of that (36.2%) coming from private insurance, leaving the remaining 17.3% to be paid out-of-pocket. However, as noted in Appendix B to the case, health expenditures can be highly skewed, and those individuals unfortunate enough to contract certain diseases may be faced with very high costs that may or may not be picked up by public or private insurers.

The class may wish to discuss different views about how scarce resources should be allocated (see Chapter 1, section 3.6.3, Resource Allocation/Rationing) and how this relates to views about justice (see Chapter 1, section 3.6.4, Distributive Justice).

### ***3. Discuss how financing approaches relate to such policy goals as: equity, security, liberty, and efficiency.***

Different policy goals would also affect preferred policies (see Chapter 1, section 3.3, Policy Goals). Emphasis on security would stress the importance of ensuring that people would not be denied medically necessary care because they could not afford it. For some people (and some items), the preferred approach might also place heavy weight on equity, and either distribute costs equally ("community rating") or on the basis of ability to pay (income-based payments). In contrast, those advocating "actuarial fairness" would reject cross-subsidization and prefer an insurance model that requires payment to be based on the likelihood of incurring costs. As noted, libertarianism would emphasize liberty, and argue that fairness not only precludes requiring individuals to subsidize others, but precludes mandating coverage at all (Hacker, 2008; Stone, 2008).

Note that in many countries, including Canada, there is considerable tax subsidy for health care that is not captured in health expenditure data (including the CIHI data); it includes the foregone revenue from not taxing health care premiums paid by the employer on behalf of individual employees, while allowing the employer to deduct these costs. This policy gives greater subsidy to those with the most generous benefits.

### ***4. What are the advantages and disadvantages of MSAs? If you decide to implement MSAs, how will you deal with the following issues: What medical services can they be used to***

***purchase? Where does the money for the allowance come from (government? employers? individuals?) Should the allowance be uniform, or vary (and, if so, on what basis)? What should be done with unused funds?***

Any MSA plan incurs added costs to payers for the allowances; these may come from employers, governments, and/or individuals forced to place some of their income into savings (e.g., the model used in Singapore). In many models, these costs are tax deductible, which may also represent considerable costs to government. However, some of these costs may be offset if MSAs replace insurance coverage. Models relying on tax deductions also pose equity issues, with those with higher incomes likely to benefit more (Allin et al., 2009; de Looper & Lafortune, 2009; Organisation for Economic Co-Operation & Development, 2007).

If people are more cautious when spending their own money than when using “free” care, utilization may decrease. As noted, eliminating unnecessary or inappropriate care is clearly desirable; however, eliminating necessary care may be more costly in the long-term, particularly if the lack of preventive care or primary care results in expensive hospital admissions. On the other hand, if people have more resources to spend for care, utilization (and costs) may increase. MSAs also incur administrative costs, which the literature suggests can be considerable. Again, the context is important; US studies have suggested MSAs can decrease administrative costs because small claims would no longer be processed, but these findings are less likely to pertain to Canada (Hurley et al., 2008; Smith, 2001). The impact of MSAs thus depends heavily upon how the plan is designed.

MSA models represent an explicit rejection of risk pooling for those services they are intended to cover, although they may be designed to encourage individuals to save over their life cycle to defray their anticipated expenditures later in life (Butler & Sidorenko, 2007). MSA models assume that most individuals will be able to accumulate enough in their MSA to cover the costs of the services included in the MSA model. Because different models of MSAs include different services, efforts to evaluate the impact of MSAs must carefully consider how the various plans are designed, and how MSAs relate to the other financing models being used. Another source of variation is the extent that different services are seen as more or less “medically necessary”. For example, should naturopathic services be seen as equivalent to physician visits, and should either be tax-subsidized? “Use it or lose it” models may also encourage additional utilization of “marginal” care, depending on what services are included in the basket (e.g., cosmetic dentistry, holistic medicine, massage therapy).

A major policy question for any funding model is what should be subsidized, and whether MSAs are a cost-effective and fair way of accomplishing this. A US scholar has proposed using cost-effectiveness analysis to guide payment policy, with full coverage for those services yielding high benefits, and cost-sharing/private purchase reserved for those services with very low cost-effectiveness (Braithwaite & Rosen, 2007; Hoel, 2007). In contrast, MSA models leave purchasing decisions to individuals; in turn, this makes it harder to defend public subsidy of services that do not yield high benefits.

Deber and Lam concluded that the likely impact of MSAs clearly depends upon the sorts of services they are expected to cover, and the extent to which individuals already have coverage (as well as how extensive, and expensive, that coverage is). They suggested that MSA models should be reserved for services only if they match all of the following criteria:

1. Not highly skewed. For skewed categories of expenditures, almost all of those receiving allowances will not need to use them. This is both expensive and inefficient. Even the advocates of MSAs note that they are not well suited for the very sick.

2. Not highly persistent, and/or not relatively small. If costs are small, even if predictable, they should be manageable through regular household spending (e.g., food, rent). MSAs are designed for high, episodic costs that could be saved for. However, if such high costs recur in subsequent years, individuals incurring those costs will soon deplete their accounts, and would have to depend on other sources (government?) to meet their bills.

3. Not “necessary.” Most of the plans reviewed have found it expedient to exempt certain services (e.g., preventive services, chronic disease management) from MSAs or co-payments, because the adverse health (and fiscal) consequences of not using them were often higher than the costs of providing those services.

They added that, if these criteria were accepted, MSAs would play, at best, a very small role, for several reasons. In terms of cost saving, the vast majority of health expenditures are incurred by the very ill; these costs are highly skewed (and therefore violate criterion 1). For those items that violate criterion 2 because their costs are both manageable and relatively predictable (e.g., routine dental preventive care, vision care), policy makers may determine that people should be able to pay for them themselves, with a potential role for means-tested services (analogous to how housing or food may be provided and/or subsidized for those with low incomes). If there are gaps in coverage for necessary care (i.e., they violate criterion 3), it would seem advisable to provide these services in the most cost-effective way possible. Particularly where such costs are relatively skewed (e.g., outpatient pharmaceuticals, home care), one policy option might be to modernize the *CHA* and ensure that medically necessary services are provided, regardless of who provides them, or where. In conclusion, the report concluded that Medical Savings Accounts may represent high costs – for the allowances, and in increased administration – for minimal benefit, particularly if they excluded both costly services and those most important to improving health. They do not appear to have much potential to be a valuable addition to financing Canadian health care.

MSAs may also decrease bargaining power over the prices charged by providers; this was found in China (Wagstaff et al., 2009). (In theory, government could regulate these prices, but that has been seen as incompatible with the logic of competition.) Other impacts, which may not be easily quantifiable, might include impacts on equity, efficiency, patient satisfaction, and provider satisfaction. A related question is the implications for the insurance industry, particularly if MSA owners expect to purchase catastrophic insurance to cover them against major problems. Models may or may not regulate what costs insurers would be expected to assume, for whom, and at what price.

**See also in Chapter 1:**

- 3.2 Role of the State
- 3.3 Policy Goals
- 3.6.3 Resource Allocation/Rationing
- 3.6.4 Distributive Justice
- 5.2 Policy/Governing Instruments
- 5.9 Insurance, Elasticity and Moral Hazard
- 6.1.1 Public and Private
- 6.1.2 Financing and Delivery
- 6.1.3 Models of Health Systems
- 6.2 Payment Mechanisms and Incentives
- 7.2 *Canada Health Act*

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## Chapter 19: Teaching Notes

### Long-term Care Reform in Ontario: “The Long Delivery”

*Patricia Baranek, Jane-Anne Campbell, Kerry Kuluski, Christopher J. Longo, Frances Morton-Chang, Karen Spalding, Carolyn Steele Gray, Fern Teplitsky, Romy Joseph Thomas, Jillian Watkins, Anne Wojtak, and Raisa B. Deber*

#### Outcome

Debate continues. Various national commissions have recommended moving towards incorporating LTC into the publicly funded system for certain groups, but this has not happened (Canadian Home Care Association, 2008).

Ontario has moved to emphasize acute care substitution, particularly reducing the number of Alternate Level of Care (ALC) days in acute hospitals. Coupled with capped budgets for CCACs, this has meant that it is more difficult to obtain LTC services for many populations. Ontario did move to attempt to regulate the quality of care in retirement homes; the *Retirement Home Act* was passed in 2010. However, for payment purposes, such homes are considered private dwellings; government does not pick up the costs for shelter, food, or other services, but individuals living in such homes are eligible to receive government-paid CCAC services.

#### Possible Points for Discussion:

##### **1. What is LTC and what types of services can it include? For whom?**

As noted in the case, LTC can include a variety of potential services, delivered to a variety of clients, in a variety of settings.

##### **2. Who should pay for what? How do the Canada Health Act definitions affect this? How does this relate to concepts of the proper role of the state?**

As noted in Chapter 1, section 7.2 (*Canada Health Act*), provinces are required to fully cover medically necessary care only if it is delivered in hospitals or by physicians. Accordingly, most care delivered in the community falls outside the requirements of the *Canada Health Act*. Provinces can (and often do) cover some of these services, but they do not have to. The class may wish to address the extent to which decisions about public financing should be based on income (e.g., means testing), and/or set service limits (e.g., maximum numbers of hours per week/month).

There are also key differences by types of service. Some professional services are time limited, and can be less expensively delivered in the community. One example is wound care; if home visits from a skilled professional can speed discharge from hospital, home-based care can be both cheaper, and more satisfying to clients and their families. Such services fit into the “acute care substitution” category. Who should qualify for publicly paid LTC substitution is more ambiguous, and targeting clients for prevention/maintenance even less clear. As one moves down the continuum from professional care to community support, one moves further away from the medical model toward the broader determinants of health model. Lighter care (care typically provided by community support services) has been shown to prevent deterioration and improve

health over the long-term (Hollander & Tessaro, 2001), yet can represent an “add on” cost to serve people who could have managed without those supports. Traditionally, publicly funded homecare often includes nursing, personal support and homemaking (but often only for those receiving nursing and/or personal support services). Community support services are not included in CCAC service plans, but can be provided separately by a multitude of grassroots and not-for-profit and volunteer organizations in the community. For most services, user-fees and co-payments are commonly employed (although these may be based on income).

One question is whether, and how, to target which clients receive which services. One way of representing the heterogeneity of needs is the widely-cited Kaiser Permanente triangle, which is being used by the UK Department of Health (Nolte & McKee, 2008). This triangle divides potential clients into three categories. Level 1 is the base of the triangle; it includes the lowest needs population, which accounts for 70-80% of the LTC population. They may need some assistance with self-care and management, but do not require more extensive services. In contrast, Level 3 clients, representing 3-5% of the LTC population, need intensive assistance, including active case management and integrated service delivery. Level 2 is in the middle, and includes individuals who may be at high risk of moving into Level 3 without proper support.

Deciding which groups to target (and how to do so) clearly becomes complicated. Should services be aimed at the highest needs group, which in turn can be justified on both moral and ethical grounds? Should services be aimed at lower needs groups in order to prevent deterioration? Leutz has argued that “you can integrate all of the services for some of the people, some of the services for some of the people, but not all of the services for all of the people” (Leutz, 1999).

Another is the nature of the services. Note that, unlike medical care, moral hazard might indeed apply to many community services. Very few healthy people would want cancer chemotherapy merely because it is free. However, many people may welcome assistance in cleaning their house, shovelling snow, or preparing meals. Accordingly, the issue of who should pay for what is less clear. One survey of healthcare providers examined views of what should be covered publicly, what should be subsidized for those unable to pay, and what should be private revealed some disagreement, but far less support for full public coverage for social services and LTC than for acute medical care (Deber & Gamble, 2007).

Note that much community based LTC is delivered by family, friends and volunteers; this may be treated differently than the professional services. There are also likely to be different views about the priority to be given to acute needs, vs. services that are intended to prevent the need for institutional care. The availability of informal caregivers (often family members) is another important variable. There is considerable debate about how much public support should be provided to such caregivers to ensure that they do not burn out. Views about what should be covered also relates to political concepts about the role of the state (see Chapter 1, section 3.2). The class may wish to discuss how different ideologies would view models of care, and how they might view a determinants of health model or a medical model.

Similarly, how important is it to treat workers well? Can, and should, efficiency come through low wages, cream skimming/risk selection, and/or skimping on quality? This is particularly problematic when outcomes are difficult to measure. The Ontario move to managed competition may have destabilized the home and community care sector and affected the ability to retain nurses, particularly when these jobs pay less than jobs in other health care sectors (Alameddine et al., 2005).

### ***3. How do these different models deal with financing and delivery of services?***

Financing incorporates a range of public (various levels of government) and private sources (including private insurance and out of pocket payment). The organizations delivering care can also be public (although this is not common in Canada), NFP, FP small businesses (usually health professionals, such as physician or physiotherapy clinics), and/or FP corporations. Different models may apply to different kinds of services.

Looking at home care, one aspect of some of these models is whether there will be a designated role for case management. Some models incorporate a single point of entry; other models leave clients and their families to attempt to navigate the system.

Another issue arises from the workings of the managed competition model, whereby providers compete for contracts (commonly referred to as the procurement process) on the basis of some combination of price and quality. Competition among agencies to receive contracts creates a clear incentive to avoid sharing best practices and innovation among these provider groups. In addition, there were often not enough competing providers offering particular services in particular areas; one result of managed competition for such services was that the costs increased (Randall & Williams, 2006). Note that the concerns raised in the procurement review (see Appendix C of the case) led Ontario to freeze new competitions and continue giving contracts to the existing providers.

Ideas also play a role. Proponents of managed competition argue that private markets lead to cost efficiencies, better choice for consumers and innovation of services. From this point of view, markets are better equipped than government to respond to health care system inefficiencies. However, opponents of private markets and managed competition in health care may argue that these models may compromise both quality of care and access to services, and to the extent that failure to use preventive services may compromise health, even increase future health care costs (Evans, 1984; Kuttner, 1999). From this point of view, it is typically argued that a strong government role (e.g., monopsony) will lead to greater macroeconomic efficiency. The class may wish to discuss when these results are/are not likely to occur.

### ***4. What policy goals are being sought, and how do these different models relate to these goals? How can the effectiveness of LTC services be measured? Discuss the implications of the production characteristics of the various kinds of LTC services.***

All of these models discussed in the case try to ensure that client needs are met (security), and that those with equivalent needs are treated equivalently (equity), at a reasonable cost (efficiency). Some also stress that clients and providers should be free to decide what services they wish to receive (liberty). There is variability in how much these goals are stressed, and in underlying theories about how best to achieve them (see Chapter 1, section 3.3, Policy Goals).

Long-term care reform provides an excellent example of how different governments frame a policy issue (see Chapter 1, section 3.4, Framing). Framing theory suggests that stakeholders (including government) may deliberately choose to present policy issues to the public in the way that can bring the most political gains to them. Framing may also be called “political spin”. Even if goals are shared, governments may choose to define or “frame” them in a way that is consistent with their own political agenda and most likely to appeal to their supporters. One useful approach is to link policies to “valence issues”, defined as issues that everyone would agree with, such reducing crime or improving health for all. By linking policy to valence issues, it is harder for groups opposed to a policy to voice their concerns.

Depending on the government and its perspective, similar policy reforms were presented

in different ways so as to gain policy support. For instance the Liberal government, in its *Strategies for Change* document, used phrases like “a coherent, well-managed system”, “promote the well-being of Ontario residents”, and “cohesive, responsive system which will enable individuals to maintain their independence”. These statements presented such goals as efficiency, independence and coherence in valence terms; few would oppose a well-managed system or argue for making a system less responsive. To focus on their priority issues of equity, workers and consumer choice, the NDP government asked such questions as: “How do we address the inequities in access and quality of service?” “As workers providing long-term care services and supports, what are your priorities for training?” and “How could a person’s ability to make a contribution towards the cost of community support services be determined so that their privacy is protected and barriers to services are not created?” The Conservative government used such words and phrases as “accountable”, “streamlining”, “level playing field”, “highest quality for the best price” and “affordability” to emphasize their fiscal consciousness. The title of their platform, *The Common Sense Revolution*, is another example of framing, for who could possibly oppose common sense?

Note that measuring outcomes can be problematic for LTC. One issue is that some costs are also benefits; labour costs may also represent local jobs. Many benefits are difficult to measure (e.g., satisfaction). LTC clients are less likely to fully recover and return to normal activities; success may instead represent better quality of life and/or increased ability to live independently, but in ways that may be hard to measure.

As noted in Chapter 1, section 5.7 (Production Characteristics), the different categories of LTC services may also have different production characteristics. Competitive models tend to work best when *contestability* and *measurability* are both high. However, many of these services would have low measurability and hence be difficult to monitor. Contestability may also vary; barriers to exit and entry may be relatively low for personal support services, but relatively high for much professional care, particularly in more remote areas, and/or for highly specialized populations (including children). These services would also have relatively high *complexity*, to the extent that they would have to be integrated with other aspects of the clients’ care.

### ***5. Who are the key interest groups and what are their likely positions? How would different models of LTC affect other parts of the health care system?***

As Chapter 1, section 4 (Interests) notes, many groups would potentially have an interest in this area. At different stages, different groups were involved (see Chapter 1, section 4.3, Scope of Conflict). The success of interest groups is dependent upon such factors as their degree of organization, the stability of membership, knowledge of government, cohesiveness, degree to which goals are focused, resources, and extent to which their political ideologies match with those of the governing party (see Chapter 1, section 4, Interests and 4.1, Concentrated/Diffuse Interests). Potential stakeholders might include organized labour (some providers were unionized, while others were not), the public (in various roles, including clients, caregivers, and taxpayers), health professionals, nursing homes, and hospitals. Note that some of these groups would be classified as concentrated interests (particularly providers), while others were diffuse interests (e.g., taxpayers). Some concentrated interests could also be limited in their availability for consultation; for example, those caring for severely ill family members were unlikely to be able to attend a public consultation.

The NDP consultations deliberately tried to bring in a wider array of stakeholders, including consumer groups and workers. Policy-making is usually limited to a relatively small

number of policy actors who share a common policy focus. Such “policy communities” (see Chapter 1, section 4.2) are often grouped around what is referred to as a “sub-government” (the key organizations or contacts that are commonly directly involved with the government in developing policy in a particular field). Policy communities, by virtue of their high involvement in a policy issue, and the specific knowledge that they can deploy when needed, may have a strong influence on policy development, although the relationships between actors within policy communities (the policy network) will be critical to how these policies are crafted.

In LTC, the sub-government would include providers (e.g., nurses, physicians, hospitals, nursing homes, community agencies, etc.) as well as patient groups.

Policy communities are usually stable over time, with membership drawn from large powerful established associations and organizations. However, sometimes governments act to encourage particular groups to be included in a policy community. For example, the NDP provincial government sometimes sought out consumer and advocacy groups, even giving funds to some consumer associations so that they could work more effectively with them.

#### ***6. How might local factors affect your answers (e.g., urban and rural areas)?***

One issue is where services are managed. As noted in Chapter 1, section 2.1.2 (Levels of Government), responsibility can rest at many levels. LTC reform in Ontario has involved shifting responsibility for some services to a regional level, which involves transfers from both the provincial level, and the local level. To the extent that effective delivery of home and community care depends on the availability of resources in that community, there is likely to be considerable variation. As one example, home visits are more difficult to arrange in rural areas, and it may be more difficult to remain safely at home (Williams et al., 2009a; Williams et al., 2009b). Reasons include such factors as: long distances, low population density, unavailability of family care-givers, poor transportation and lack of access to health and social services. Distance and access issues may exacerbate broader health determinants, including poverty, discrimination, and lack of investment in health education and literacy. Older people in small and rural communities are often at greater risk of being placed in a nursing home, even though they may have the same, or even lower, level of care needs than their urban counterparts, because of difficulties in obtaining home based support. Challenges to care delivery can include: workforce supply and access to integrated health and social services (requires interdisciplinary teams, alternative caregivers, varied professional and allied health provider mixes and collaboration among rural and remote health workers via video, computer or phone line teleconferences (Lum & Aikens, 2010).

#### **See also in Chapter 1:**

- 2.1.2 Levels of Government
- 2.2.4 Regional Authorities in Canada
- 3.2 Role of the State
- 3.3 Policy Goals
- 3.4 Framing
- 4 Interests
- 4.1 Concentrated/Diffuse Interests
- 4.2 Policy Communities
- 4.3 Scope of Conflict
- 5.7 Production Characteristics
- 6.1 Dimensions of Health Care Systems

- 6.1.1 Public and Private
- 6.1.2 Financing and Delivery
- 6.1.3 Models of Health Systems
- 6.3.2 Sickness Care Subsectors
- 7.2 *Canada Health Act*
- 9.1 Canadian Data

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## Chapter 20: Teaching Notes

### Depending on How You Cut It: Resource Allocation by a Community Care Access Centre

*Jane-Anne Campbell, Heather Chappell, Joanne Greco, Jeff Hohenkerk, Joshua Kline, Shannon L. Sibbald, Karen Spalding, Fern Teplitsky, Anne Wojtak, and Raisa B. Deber*

#### Outcome

Because this is a hypothetical case set in a non-existent CCAC, there is no outcome *per se*. Questions do remain about how CCACs should make these decisions, and the extent to which these should be uniform across the province or be tailored to local circumstances. There are also ongoing questions about who should be served, and what services should be provided without charge. One debate has been about the balance between the *acute care substitution* function (in particular, enabling hospitals to discharge patients), the *long term care substitution* function (enabling people to avoid being placed in nursing homes), and the *prevention/ maintenance* function (Dumont-Lemasson et al., 1999). The trend has been to give priority to those being discharged from hospitals, often to the detriment of those needing social supports to allow them to remain in their homes. There have also been questions about whether the amount of services for individual clients should be capped (to allow resources to be spread more widely) or focused on those with the greatest need. With a limited budget, giving more resources to the children and their families might mean being unable to serve such other populations as seniors and those being discharged from hospitals.

Attempts to reduce hospital stays and close hospital beds have also increased the demand for CCACs to serve Alternate Level of Care (ALC) patients. Although there have been calls for the federal government to fund a national home care program, little has happened.

The example of Cathy and Tim described in the case can be used to show how decisions made at the meso (organizational) level affect real people, to highlight the multiple and varied needs of individuals within the community, and to enhance discussion about claims of individuals and what corresponding obligations the government has to the disabled (Kilner, 1995).

#### Possible Points for Discussion:

##### ***1. What services should be provided, and to whom? Who should pay for what? What are the roles of: individuals, families, charity, and government?***

The issue about who should pay for what rests on values and ethical principles. To what extent are people interdependent? What is the role of individuals and their families? Charities? A wider community? As noted in Chapter 1, section 3.2 (Role of the State), different ideologies take different views of the role of the state.

A related question is how one defines a community (see Chapter 1, sections 3.3, Policy Goals, and 3.3.3, Equity). It can be defined narrowly as people I know. It can be widened to those living in my neighbourhood, my local community, my province, my country, or even on my planet.

These judgments may also depend upon the type of services. Demand for medical services tends to be less susceptible to moral hazard (see Chapter 1, section 5.9, Insurance, Elasticity and Moral Hazard). People are unlikely to request cancer chemotherapy if they do not have cancer, merely because it is free. Social services, in contrast, can be highly susceptible to moral hazard issues; people might well be pleased to accept free housekeeping or snow shoveling, or meals on wheels (assuming these meals are of good quality). Distinguishing between “wants” and “needs” for such services can become much more problematic (Deber & Gamble, 2007).

As noted in the case, none of these community LTC services fall under the comprehensiveness conditions of the *Canada Health Act* (see Chapter 1, section 7.2). However, some services, for some clients, can be cost-effective substitutions for more expensive care. The obvious example is care that allows people to be discharged from hospitals earlier (acute care substitution). Care that can prevent hospital admission may also be cost-effective, but only if such a hospital admission would otherwise have occurred. Many clients could potentially benefit from community long-term care services; the question of where one should draw the boundary for which of them will receive services (and at what cost to them and their families) is a difficult one that remains unanswered, yet is fundamental to a CCAC board’s attempt to allocate resources fairly to those in need.

Another issue is that, despite widespread use of home care, there are very few studies on its cost-effectiveness. Services are unlikely to be randomly assigned, and differences between subpopulations may account in part for differences in outcomes. A series of studies at the University of Toronto have used the Balance of Care model and estimated that a significant proportion of those individuals assessed as having needs that were sufficiently high to qualify them for placement in LTC facility could still be supported safely and cost-effectively in their home (or in supportive housing) with an appropriate basket of such services as housekeeping, nutrition, and transportation; however, others could not, while another group could manage even without such support (Williams et al., 2009a, 2009b). One key element is the availability of informal caregivers, although these caregivers may also require support. In this case, the parents of these children were trying to care for them, and were burning out. A question without a clear answer is the boundary between what families should be expected to do for their family members, and what would be deemed excessive and hence to warrant help from their broader community.

As noted in Chapter 1, section 3.2 (Role of the State), one set of issues relates to rights/entitlements. The language of rights is powerful. To the extent that the parents of the disabled children can frame the question in terms of their “rights” to receive help, they may be more successful than if the question is framed as taking resources away from seniors to help children (see Chapter 1, section 3.4, Framing).

Several ethical frameworks attempt to evaluate the *fairness* of decision making. Elements include consideration of the outcomes, and/or of the process being followed. As noted in Chapter 1 (sections 3.6, Ethical Frameworks, 3.6.3, Resource Allocation/Rationing, and 3.6.4, Distributive Justice), there are multiple principles that could be considered. Is it fair to give everyone the same amount, or to give more to those deemed to have the greatest need? How much more? How is this determined? One possible way out of this dilemma is to focus only on the process by which resources are allocated, rather than the outcomes.

The Accountability for Reasonableness framework (see Chapter 1, section 3.6.1) suggests four conditions, and argues that if they are met, the decision is fair (Daniels, 2000). The

conditions suggested are the following: *Relevance is defined as stating that the rationales for priority setting decisions must be based on reasons (evidence and values) that stakeholders can agree are relevant.* Procedurally, having a wide range of stakeholders participate in deliberation is said to ensure that the full range of relevant reasons will be considered. *Publicity* suggests that priority setting decisions and their rationales must be publicly accessible, not just on demand, but through various forms of active communication outreach. *Revisability* notes that there must be processes for revising decisions and policies in response to new evidence, individual considerations, and public reactions. *Enforcement* argues that local systems and leaders must ensure that the above three conditions are met. The class may wish to discuss whether they consider these principles appropriate, as well as how well the CCAC process would ensure that clients and potential clients would be satisfied. Are fair processes enough, or do outcomes also matter? If outcomes also matter, what other approaches might work? (Clearly, there are no easy answers.)

**2. Resource allocation decisions take place at many levels, including macro, meso, and micro. How should these decisions be made? Who should make them? How much variation across CCACs is appropriate? What is a fair distribution?**

As noted in Chapter 1, section 3.2 (Role of the State), governments may differ in the extent to which they are willing and able to support their citizens. Particularly in times of economic difficulty, where governments are trying to reduce their deficits, they are likely to be unwilling to extend entitlements. At the same time, citizens who have been affected by a poor economy are likely to need more, rather than less, help.

Resource allocation is commonly classified in terms of three levels of decision-making: macroallocation, mesoallocation, and microallocation (recognizing that the boundaries between them may be fuzzy). *Macroallocation* decisions determine the resources available for particular kinds of services at the societal level. In this case, we could argue that the government's decision of how much to fund health care, and within that, how much to give the CCAC would be a macroallocation decision. (Enforcing a set budget becomes easier when the money is provided through an annual budget, rather than through other volume-sensitive and hence open-ended mechanisms such as fee for service; see Chapter 1, section 6.2, Payment Mechanisms and Incentives.) *Mesoallocation* involves decisions at the organizational level around how money is allocated within their budget for the provision of particular services. *Microallocation* focuses on decisions regarding services for individual persons. In this case, the CCAC case managers would make these sorts of microallocation decisions as to who will receive which services. Decisions made on each level affect the other levels (e.g., the decision of the government to give the CCAC \$48 million as a global budget will influence decisions at the meso and micro levels). Thus, the decisions made at each level are closely linked. Although this case focuses mainly on the meso level (the decisions of the CCAC board), considerations at the macro and micro level will also affect these decisions.

At the macro level, the provincial government decides how much of the total government budget should go to health care, and within that health budget, how much money should be allocated to individual programs (although this might also be seen as a meso level decision). The government may or may not decide on standards of quality for service provision, as well as how much decision-making authority should reside with the organizations responsible for providing services. Note that under the *Canada Health Act* (see Chapter 1, section 7.2), there is no requirement for government to pay for home and community services unless these are delivered

by physicians. Provinces can choose to do so, but do not have to. However, they do need to fully insure hospital services. Unsurprisingly, many provinces, including Ontario, have emphasized acute care substitution in an effort to reduce hospital costs by ensuring that discharged patients will receive the care they need (on a short-term basis) to enable them to leave the hospital, and to prevent unnecessary readmissions. This may also involve shifting the costs from government to patients and their families.

In Ontario, Bill 173, *The Long-Term Care Act*, set out the legislative framework for planning, managing and delivering community long-term care services. This legislation, passed in 1994 by the NDP government, identifies four categories of mandatory long-term care community services: 1) community support (e.g., meal services, transportation, adult day programs and friendly visiting), 2) homemaking (e.g., housecleaning, laundry, ironing, mending and shopping), 3) personal support (e.g., routine activities of daily living), and 4) professional services (e.g., nursing, occupational and physical therapy).

There are multiple ways to pay for these services. In 2002, the Standing Senate Committee on Social Affairs, Science and Technology (the Kirby Report) had suggested four possibilities for a federal role: 1) a national home care program; 2) tax credits and tax deductions to home care consumers; 3) creating a dedicated insurance fund to cover the need for home care, and 4) specific measures aimed at supporting informal caregivers (Standing Senate Committee on Social Affairs Science and Technology, 2002). Their report had suggested that the *Canada Health Act*'s definition of medical necessity should be extended to include post-acute home care (post hospital discharge) and palliative home care programs. The same year, the Royal Commission on the Future of Health Care in Canada (the Romanow Report) reported. Its home care-related recommendations included: a separate federal home care transfer to the provinces for providing home care services; revising the *Canada Health Act* to include such priority home care services as mental health, post-acute and palliative care; and establishing a national program to provide support for informal caregivers (Commission on the Future of Health Care in Canada, 2002).

The Ontario government has attempted to download difficult resource allocation decisions to individual CCACs by capping their budgets and leaving them to make the micro allocation decisions within that budgetary constraint. As noted in Chapter 1, section 2.1.2 (Levels of Government), there are different ways to divide powers among levels of government. One key distinction is between devolution and decentralization. *Decentralization* is a process that physically locates services locally while retaining authority for their provision centrally. *Devolution*, on the other hand, refers to a transfer of responsibility for planning, coordinating, and/or delivering services to a local body which may be given the ability to take into account local needs, conditions and preferences. Models vary in terms of how much autonomy these different bodies are given. For example, in Ontario, the CCACs and Local Health Integration Networks (LHINs) would formally be categorized as devolved authorities, but the province funds them, and gets to set the rules (see Chapter 1, section 2.2.4, Regional Authorities in Canada). In theory, provincial governments can avoid being blamed for resource allocation decisions made by these regional bodies; in practice, this does not always work, and many complaints about their decisions are still raised in the provincial legislature and the media.

### **3. Discuss the role of interests.**

Whenever decisions create winners and losers, the losers may seek to change these decisions in their favour. As noted in Chapter 1, section 4 (Interests), pressure groups are defined

as “organizations whose members act together to influence public policy in order to promote their common interest” (Pross, 1992). These groups vary in how powerful they are. Certainly, the parents of children with long-term needs are unlikely to have the resources to continually monitor policy and ensure their interests are being pursued (Peter et al., 2007; Spalding & Salib, 2008). In contrast, certain provider groups may well have such resources, and even become parts of the policy community involved in setting policy. Similarly, groups representing seniors are likely to be better organized than those representing children with severe disabilities and/or chronic illness. The class may wish to discuss who is likely to be part of the policy community on these issues, and which of these groups would be part of the sub-government, vs. being part of the attentive public (see Chapter 1, section 4.2, Policy Communities).

The class might also wish to discuss the possible implications of the scope of conflict (see Chapter 1, section 4.3, Scope of Conflict). This theory, associated with Schattschneider, stresses the importance of where decisions are made, and who is at the table. Resource allocation decisions could be made within governments (e.g., passage of laws, in this case at the provincial level), within bureaucracies (e.g., within the CCAC), or by courts (e.g., decisions relating to rights and entitlements). These different venues would usually have different rules, and empower different interests, often leading to different policy results.

#### ***4. How does street-level bureaucracy affect the decision of the CCAC board?***

Allocation decisions at the micro level focus on what services to provide to individual persons. CCAC case managers have a large degree of latitude over who to give services to and who not to provide services to. The CCAC Board will have to take into account the relative autonomy of case managers when making decisions. If case managers’ decisions vary widely, access to services may also vary inequitably within the boundaries of a certain CCAC. The Board will have to decide how best to standardize the decisions of case managers without expending too many resources on doing so or losing necessary flexibility to respond to differences in the needs of ostensibly similar clients.

Although the board of directors of each CCAC has authority regarding how to allocate funds from their budget, it is the front-line staff members at the CCACs who ultimately grant access to government programs and provide services to the individuals in the community. How closely should CCAC boards control (micromanage) these staff people through strict guidelines and criteria? More importantly, to what degree will they actually be able to control these staff members who have the discretion to approve long-term care services in the community? The concept of street-level bureaucracy (see Chapter 1, section 5.3, Street-level Bureaucracy) notes that certain categories of workers, including police officers, social workers, and home care workers, by the nature of their job, work outside office settings, have significant interactions with citizens/clients, and have substantial discretion over how they do their work (Lipsky, 1980). It is difficult for their organizations to manage these frontline workers; there is instead heavy reliance on professionalism (see Chapter 1, section 6.4, Professionalism). To the extent that those assessing clients qualify as street-level bureaucrats, regardless of the intentions of the agency, implementation of policy at the client level may vary from one provider or service to another. Therefore, even if there are service maximums in place for specialized populations, such as children, it is not clear whether case managers will follow them, or will seek to work around them in what they see as the best interests of their clients. Discretion over provision of services is thus likely to vary between and within CCACs.

### ***5. Discuss the options available to the board, and their strengths and weaknesses.***

The options presented have advantages and disadvantages. One issue is the basis on which the choices are made. The class may wish to discuss the potential contributions of such frameworks as economic analysis, or resource allocation ethics.

Among the options available to the Montgomery CCAC is to base its funding allocation decisions on the types of services, and/or the types of clients they serve. Although this is not currently permitted by MOHLTC policy, in some jurisdictions agencies may decide to “means test” the clients based on their ability to pay in order to keep the overall costs within budget. Another option is to decide which individuals in their community are in the most need of services and preferentially provide services to this limited number of high-need clients, which might include children with disabilities. They could also try to obtain services more cost-effectively.

Because the CCAC does not directly provide services, they have some control over who receives the contracts to provide the services the CCAC has deemed important to provide. Decisions about which providers to contract with revolve around what services they can provide, quality of care, and even issues of employment fairness. The CCAC model incorporates a “managed competition” or “mixed market” model (see also Chapter 19, Long Term Care Reform in Ontario), which attempts to use competition between multiple providers, regulated so that this competition incorporates quality rather than only price, in an effort to attain both cost savings and high quality. In theory, these choices are made on the basis of “highest quality, best price”. In practice, it has proven very difficult to assess quality. Certainly, the quest for lower prices has led to changes among home care providers. There are differences in how staff is paid and the mix of staff being used (e.g., fewer full-time employees). There is some evidence that competition has been destabilizing; for example, one study found that retention for Ontario nurses working in the community sector was much lower than for nurses working in the hospital sector (Alameddine et al., 2005). A related option that has been used is to replace professional staff (i.e., home care nurses) with lower paid unregulated workers who can provide some of the same services in the home that nurses do, at a much lower cost to the organization. The implications for quality are less clear.

Another option is to “protect” certain services. Within global budgets, all programs compete with each other for funding. Protected budgets can be created to guarantee levels of funding for programs that would likely not do as well within a global budget because of their relatively lower level of political support. In this way, important programs without organized lobby groups can be protected. In this case, some of the funding for children’s services could be placed in a protected budget so that they would not have to compete with services for the elderly. Capping costs and shifting responsibility for what would be purchased with that money to the client is another option; it assumes that clients are willing and able to hire and supervise their own staff, and downloads the decisions about what to buy with the available resources to the client. Again, the extent to which strings should be attached to how public money is spent is a matter for debate.

### **See also in Chapter 1:**

- 2.1.2 Levels of Government
- 2.2.4 Regional Authorities in Canada
- 3.2 Role of the State
- 3.3 Policy Goals



- 3.3.3 Equity
- 3.4 Framing
- 3.6 Ethical Frameworks
- 3.6.1 Accountability for Reasonableness
- 3.6.3 Resource Allocation/Rationing
- 3.6.4 Distributive Justice
- 4 Interests
- 4.2 Policy Communities
- 4.3 Scope of Conflict
- 5.3 Street-level Bureaucracy
- 5.9 Insurance, Elasticity and Moral Hazard
- 6.2 Payment Mechanisms and Incentives
- 6.3.2 Sickness Care Subsectors
- 6.4 Professionalism
- 7.2 *Canada Health Act*

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## **Chapter 21: Teaching Notes**

### **Shoot and Tell: Mandatory Gunshot Wound Reporting by Physicians**

*Carrie-Lynn Haines, Julie Holmes, Paul Miller, Sharon Vanin and  
Raisa B. Deber*

#### **Outcome**

As noted in the case, at the time of writing, similar legislation was also in place in Alberta, British Columbia, Manitoba, Newfoundland, Nova Scotia, Quebec, and Saskatchewan. Two years after the proclamation of the *Mandatory Gunshot Wounds Reporting Act*, a study evaluating the impact of and response to this new law concluded that the legislation seemed to have been broadly accepted by the providers of emergency services community and endorsed by the public (Ovens et al., 2009).

#### **Possible Points for Discussion:**

##### ***1. What kind of a public health risk does violent crime pose? How does this risk compare to child abuse? Spousal abuse? Infectious diseases?***

Two sets of arguments have been made in support of mandatory reporting of gunshot wounds, one based on protection of the public, and the other on violence prevention. The main rationale underlying these arguments is that the more we know about the causes and the incidence of gunshot wounds, the more proactive we can be about prevention using a broad public health approach (see Chapter 1, section 6.3.1, Public Health) while also aiding the ability of the police to protect the public from the perpetrator.

In most large cities (including Toronto), with rare exceptions, the police would be involved in every gunshot wound case before the victim would be taken for assessment to a hospital emergency department (ED). Particularly if a call was made to 911, most jurisdictions would use a tiered-response process that involves police when seen appropriate; this process does not have the same confidentiality requirements for physicians and hospitals as described under the *Regulated Health Professions Act* and the *Personal Health Information Protection Act*. However, as the injuries/crimes under discussion become more minor, the likelihood of police and 911 involvement becomes less. Such relatively minor events, however, do comprise the vast majority of violent crime seen in the ED and may also have a significant cost to society. Unreported gunshot wounds are an extremely rare situation and therefore have a reasonably small public health risk. The relative likelihood of such unreported shootings may be largest in rural areas, although these tend to involve accidental rather than intentional shootings.

Disease prevention is facilitated when good data is collected, including information to help determine the root causes of episodes of ill health. Public health units and associations are, with increasing frequency, declaring violence to be an issue of concern to public health and an important determinant of health, especially in children.

The class may wish to discuss the similarities and differences among such potentially reportable events as child abuse, impaired driving, infectious diseases, and gunshot wounds and the other types of events noted in Appendix B of the case. Rationales for intervention are varied,

but usually concern threats to the public. For example, children are a vulnerable group and usually require the help of others to prevent ongoing abuse. Impaired drivers represent a clear risk to others using the roads, and the removal/suspension of their licenses should (at least in theory) decrease that risk. Similarly, doctors may be asked to report patients who should no longer drive because their eyesight is impaired. Patients with infectious diseases may pose a direct risk to others, and intervention can mitigate or eliminate the risk (at least in theory) (Ovens, 2004; Pauls & Downie, 2004a, 2004b).

***2. How should violence be defined for the purposes of reporting? Should it apply to gunshots only? Stab wounds? Should it matter whether these were intentional or unintentional?***

From a public health perspective a violent crime can take many forms, from verbal attacks to murder. The negative impact of many such events is not solely determined by the event, but also must consider the impact of that event on the victim(s). From a legal point of view, one may argue that only violent events that break the law should be reported to the police. However, people may report abusive acts to children's and family services even if these do not breach the criminal code. This question of "degrees" of violence does not have a clear answer.

Extending mandatory reporting to include stab wounds would probably improve the data for prevention programs. For example, in 2007, one analysis of penetrating trauma in Ontario emergency departments found both that such injuries were relatively rare (3.4% of the 1.2 million ED visits in 2002-03 for trauma, or 40,240 cases), and that most were the results of knives or sharp objects; only 1.5% of the injuries related to penetrating trauma had been caused by firearms (Macpherson, 2007). However, there might be adverse consequences (potentially warranted) for those inflicting such injuries if they were reported to police.

In 2009, the Ontario Medical Association (OMA) Emergency Medicine section published a statement reaffirming their position that, although they supported mandatory reporting of gunshot wounds, they did not support mandatory reporting of other violent injuries, including stabbings. Their rationale was that gunshot wounds were both more lethal, and could pose "a public health risk to people in the vicinity when the trigger is pulled". As noted in the case, the OMA Emergency Medicine section concluded that, "The huge burden that knife wound reporting would place on health care workers and police is extremely disproportionate to the minimal potential health benefit".

Others have noted the possibility that victims, depending on the severity and location of the wound, may avoid seeking medical care for fear of being reported to police, and may become more reluctant to disclose relevant information to the attending physician if there are damaging circumstances surrounding their injuries (e.g., family violence situations, potential threat of harm to the safety and security of other family members).

Another concern is that voluntary reporting opens the possibility of coercion and threat to front line providers. This policy may also force workers to justify why they did not report an event that others thought met the criteria for a "reportable event". Several groups representing health providers commented on these possibilities during the government debate on gunshot legislation. Current legislation in Canada for gunshot trauma has steered clear of legislating penalties for those people that do not comply with reporting requirements. In the US, several states have threatened imprisonment for providers who refused to comply with reporting gunshot wounds. Relying on voluntary reporting could increase the amount of variability in the data collected, which may also have an impact on the utility of the data for research.

***3. What are the ethical issues involved? How would this be affected by how the question is framed (including the appropriate balance between societal protection and confidentiality when confronted with a violent crime)?***

One policy issue is how to weigh potentially conflicting policy goals (see Chapter 1, section 3.3); these may include preventing recurrence, punishing the offender, and providing care to individuals in need. Ethical frameworks (see Chapter 1, section 3.6) may give different answers, depending on how the question is asked, and whether the key responsibility is seen to be to the individual patient (and his/her confidentiality) or to society. A healthcare professional may also object to mandatory reporting on pragmatic grounds if they believe that it may create more harm than good. Potential risks of mandatory reporting could include retaliation by the abuser/perpetrator and concern about breached confidentiality, which could damage the trusting relationship between the victim and the healthcare provider. Although healthcare providers are required by law to breach their duty of confidentiality to report gunshot wounds, this could negatively affect their relationship with patients, the foundation of which should be frank and transparent communication aimed at serving the patient's best interests. This is only possible if a patient trusts their healthcare provider. Anything that could compromise this trust could ultimately deter victims from seeking help or returning for healthcare services. This could in turn jeopardize the safety of such potentially vulnerable individuals (particularly abused family members).

Some believe that the law takes away the ability of competent health care professionals to independently exercise judgment and make decisions. There is a perception among some healthcare providers that disclosure should depend on professional assessment of not only the injury, but of the context in which it occurs. In this view, mandatory reporting of health information to the police does not serve the interests of those individuals or even of the health system as much as the ability to prosecute crimes (a criminal law purpose). In that case, they argue that such legislation falls outside the provincial entitlement to regulate health information.

The class may wish to discuss how different ways of framing the policy issue (see Chapter 1, section 3.4) in turn affect what policies are recommended.

Healthcare provider groups are concerned about the frequency with which patients involved in trauma or violence may not present to hospital EDs for care if they are afraid of breeches of confidentiality and trust. At the same time, police services may experience difficulty in obtaining information about individuals who go to EDs with wounds indicative of criminal activity. Based on the low rates of victim reporting for violent crime (particularly domestic violence), this reinforces the possibility noted above that these patients may be demonstrating a desire not to involve police for personal reasons (including self protection). In the US, 48 of 50 states currently have legislation that requires reporting of gunshot wounds. A study of American inmates found that, on average, 9% of their sample had not reported to hospital after being shot. That number was as high as 19% in some jurisdictions.

Available statistics on violence involving guns calls into question whether a police investigation is the most effective and efficient way to prevent further violence and protect the public. It has been suggested that education and safety training would be a better strategy for preventing accidental firearm injuries and deaths than police notification. Those analysts would further argue that patients who attempt suicide with a firearm would usually require psychiatric care, and that the victims of accidental and self-inflicted gunshot wounds (the majority of cases) pose little risk to the public at large. Others disagree.

**4. Who should be responsible for reporting? To whom should that report go? What are the options? Are there trade-offs that need to be considered?**

The challenges of mandatory reporting hinge on the fact that healthcare providers and healthcare facilities don't release patients' personal health information to anyone, with few exceptions for specific circumstances as permitted by law. One of the sticking points for physicians is that reporting of gunshot wounds or other violent crime is the first case of reporting patients' personal health information directly to the police who are not currently bound by the *Personal Health Information Act*. The information that must be reported varies depending on the agency taking the report. Police would likely ask very different questions than would a public health nurse. Likewise, the ramifications of involving the courts would be very different than the implications of involving Children and Family Services. Several times during the debate of Bill 110 (the precursor to Ontario's *Mandatory Gunshot Wounds Reporting Act*) an important question surfaced: Why does a Bill which is intended to aid law enforcement not compel more information for the police than simply the name of the victim?

As noted above, trade-offs may also include the fear that providers may be subjected to repercussions for their reports. Those fears, whether founded or not, may be different depending on who the report is sent to and how the report is handled (i.e., anonymous, mandatory report to public health vs. voluntary, full disclosure to police).

**5. What policy options might help reduce the risk of violent crimes?**

One analysis suggested a series of possible public health strategies to address violence (Macdonald, 2002). Prevention can be sub-divided into: primary prevention (which seeks to avoid occurrence of disease); secondary prevention (which seeks to diagnose and treat disease at an early stage and hence avoid mortality and morbidity if possible); and tertiary prevention (which seeks to restore function and reduce disease-related complications once someone is ill). At the *primary prevention level*, approaches to violence prevention could involve such population-wide measures as: violence risk education for all school students; parenting education for all new parents; targeting communities where violence is more endemic with appropriate risk reduction strategies, such as street lighting, surveillance and cameras and community policing; reduction in mass media portrayal of violence; and/or poverty reduction strategies. At the *secondary prevention level*, approaches could involve: support counseling and post-traumatic counseling for victims of violent crime; peer mediation techniques to resolve disputes in schools or the workplace; home visits to families identified as having a high risk of domestic violence or child abuse; and/or violence prevention coalitions targeted to high-risk neighborhoods. At the *tertiary prevention level*, approaches could involve: appropriate treatment/rehabilitation for violent offenders; improving parent management strategies and child bonding techniques in families with violent children; adequate shelter provisions for victims of domestic violence; training and strategies for health and social care professionals in identifying and referring victims of family violence; and/or increasing the penalties for perpetrators of violent crimes. The costs and consequences of these interventions clearly vary. Specific policy options might include:

1) *Mandatory reporting of all cases of criminal activity*. This would require a new piece of legislative authority that would legally protect and mandate physicians that report on a wide range of illegal (or potentially illegal) activity, these could include cases of drug intoxication, impaired driving, illegal immigration, some sexual acts as well as injuries thought to have been sustained while breaking the law (i.e., fight injuries, lacerations from fences/windows, and drug

use). This would leave very little discretion to providers about what to report, and would greatly sway the balance of personal privacy in favour of the state.

2) *Mandatory reporting of certain types of criminal activity.* Extension of mandatory gunshot wound reporting legislation to include stab wounds has been enacted in some Canadian jurisdictions. Such policies could potentially include reporting other violence-induced injuries as well. This would remove the judgment of clinicians to some degree but would still limit the types of cases considered “reportable offenses”. This option hinges on the definition of “violence” and would vary depending on the types of situation.

3) *Voluntary reporting of criminal acts with or without the consent of the individual involved.* This would require a higher degree of judgment on the part of healthcare providers to balance the relative risks and benefits to the patient and/or the community. In this case, presumably the issue of physician and/or hospital liability for breaching confidentiality would have to be addressed in legislation. The types of “reportable” events could vary heavily from one provider to the next and might create uncertainty in the provider community about one’s responsibility to report.

4) *Increased educational support to address the connection between the social determinants of health and gunshot wound reporting.* This would redirect the responsibility from the role of the healthcare provider to the role of the social system in identifying where the biggest impact for the betterment of society lies. For example, more than half of all homicides committed in Canada with a firearm in 2009 were gang-related. Statistics Canada reports that the incidence of gang-related crime has increased in recent years. In 2010, 94 homicides in Canada were considered to be gang-related. The number of youths ages 12-17 accused of homicide was small; 56 in 2010 down from 79 the previous year. (Brennan & Dauvergne, 2011) Assessing the epidemiology of the issue and targeting the root cause as it relates to societal breakdown might be another option.

Clearly, various policy instruments could be used (see Chapter 1, section 5.2). The policies noted above rely heavily on regulation and on information/exhortation. However, a focus on prevention might also call for use of expenditure instruments.

5) *Increased support of healthcare provider confidentiality.* This would place emphasis on the individual’s right to privacy of personal health information. It might imply weakening the current mandatory reporting conditions and leaving more to the judgment of the provider about when to report.

### **See also in Chapter 1:**

- 3.3 Policy Goals
- 3.4 Framing
- 3.6 Ethical Frameworks
- 5.2 Policy/Governing Instruments
- 6.3.1 Public Health
- 6.4 Professionalism

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## Chapter 22: Teaching Notes

### **Dying to Die: Euthanasia and (Physician-) Assisted Suicide**

*Christopher A. Klinger, Joe Slack, and Raisa B. Deber*

#### **Outcome**

In June 2012, the British Columbia Supreme Court declared the Criminal Code provisions prohibiting doctors from helping their patients to commit suicide to be unconstitutional, and gave the Canadian Parliament one year to “take whatever steps it sees fit to draft and consider legislation”. Plaintiff Gloria Taylor was also granted a constitutional exemption allowing her to legally commit suicide with the help of her doctor, as long as specified conditions were met; these required that the physician attest that she was terminally ill with no hope of recovery and that she was informed about her prognosis, options, and risks; that both her physician and a psychiatrist attest that she was competent; and that the physician-assisted death be performed by her (unassisted) unless she was physically incapable of doing so. The federal government announced that it would appeal this decision to the Supreme Court of Canada. A hearing before the BC Court of Appeal was held in March, 2013; at the time of writing, no decision had been announced.

The issues remain hotly debated. In late 2011, The Parliamentary Committee on Palliative and Compassionate Care had issued a report calling for better palliative care (Albrecht et al., 2011). A Royal Society of Canada Expert Panel report on End-of-Life Decision Making recommended against interfering with requests for assisted suicide or voluntary euthanasia “for competent and informed individuals who have decided after careful consideration of the relevant facts, that their continuing life is not worth living” (Schuklenk et al., 2011). Others continued to disagree. Gloria Taylor did not need to use the exemption; in October, 2012, she died suddenly after a severe infection resulting from a perforated colon; her family described her death as quick and peaceful.

#### **Possible Points for Discussion:**

***1. Should euthanasia and physician-assisted suicide be permitted? If yes, what restrictions/limitations, if any, should be imposed? How, if at all, should vulnerable populations be protected (e.g., against pressure to end “unproductive lives”)?***

As noted below, views on these issues are heavily dependent on one’s religious, moral, and ethical beliefs. There are no correct answers. As discussed in the case, one can de-compose views into the series of questions raised by Bülow et al. (2008).

- Is it appropriate to withhold treatment? Does this depend on how likely the treatment is to work? On how much it would cost?

- Once treatment is started, can it be withdrawn? Again, what should this depend on? How well it is working? How burdensome it is? How painful? Whether it is deemed established therapy, or experimental?

- Once artificial nutrition (tube feeding) is started, can it be withdrawn? How about artificial aids for breathing?

- Can the “double effect” could be employed (as noted in the case, this refers to administration of medications with the goal of alleviating pain, but which might also,

unintentionally, hasten death). If yes, what is to prevent a “wink wink nudge nudge” approach where the hastening of death is unintentional only for official purposes?

- Is euthanasia itself accepted?

The background paper for the Library of Parliament suggested the following issues that would need to be decided should new legislation be passed on the subject of euthanasia and assisted suicide (Nicol et al., 2010). They specifically mentioned:

- Should euthanasia, assisted suicide, or both be legalized;
- What physical and/or mental states would be required for a person to have access to such services;
- Should minors and/or incompetent people have access;
- What process would be used to determine a person’s wishes;
- Who would be consulted (they note medical team, experts, and family as possibilities).

Jurisdictions that have legalized euthanasia and/or physician-assisted suicide have often done so with a number of stipulations in place (see Appendix D of the case). These may include issues related to:

*Diagnosis.* The possibilities may range from requiring a terminal diagnosis (with room for debate about the probability, and the time period, because estimates are just that, and people may live longer than might be predicted), to also requiring that the person faces unbearable pain and suffering. Again, there can be some debate about what might qualify, and who should define whether the suffering is unbearable. Some bills (e.g., the bill by Lalonde mentioned in the case) extended this to “physical or mental pain without any prospect of relief” (which again begs the question of how certain one must be that relief is not possible).

*Competency.* Issues include whether the patient must be deemed mentally competent and of legal age, how competency should be determined, and what should be done if the patient would not qualify as competent.

*Waiting period.* Should there be a mandatory period for reflection to protect the patient from “rushed” decisions and/or potential external influences. What if, for example, an illness is expensive and family members wish to protect their inheritance? (Lalonde’s bill also required that vulnerable populations be protected by requiring that the medical practitioner have no reasonable grounds to believe that the request was made under duress.)

*External confirmation.* The diagnosis may need to be confirmed by a specified number of physicians; this is usually set at two.

*Information.* Lalonde’s bill required that specific information be made available to the patient about the consequences of his or her request and of alternatives available to him or her, such as hospice and palliative care.

Related questions may concern issues of consent and capacity (and how to deal with patients who are no longer able to express their views), and with clinical outlook. In most jurisdictions, there are formal guidelines with regard to capacity and consent to treatment (including those incorporated within mental health acts). As noted in the case, jurisdictions permitting Advance Directives may have provision for a Medical Power of Attorney, which allows a substitute decision maker/health care proxy to act on behalf of the patient in case of incapacity.

Although exact projections of likely survival time and quality of life over time (sometimes termed “trajectories” of disease) are difficult, some organizations have developed guidelines for expected prognosis for many diseases, including cancer. For example, the US

National Hospice and Palliative Care Organization, Inc. (NHPCO) has developed a series of such guidelines.

Another set of issues arose when distinguishing between voluntary euthanasia (as illustrated by the Rodriguez case) and involuntary medically assisted death (Stingl, 2010). In particular, the case of Robert Latimer, who killed his disabled daughter, and was sentenced to jail, has been highly contentious.

**2. Discuss: the principle of autonomy. The role of religious beliefs. The slippery slope argument.**

Proponents of euthanasia and physician-assisted suicide often point to the principle of autonomy (see Chapter 1, section 3.6, Ethical Frameworks). Currently, the individual patient is considered to have the right to decide about his or her own treatment (or lack thereof). Concern for a patient's future autonomy may stand in the way of respecting autonomous decisions made at the present time, however, especially when the capacity for autonomy is in question (Levi, 1999).

The *slippery slope argument* fears that allowing physician-assisted suicide might lead to encouraging those with disabilities to kill themselves (involuntary euthanasia); others argue that this has not materialized in those jurisdictions allowing the practice. Nevertheless, severe or terminal illness can create pressures that would need to be addressed, including: feeling of worthlessness and undue burden in the patient; abuse and neglect by the caregiver(s); and/or financial hardship.

A related rationale for limiting autonomy is when the person wishing to kill themselves suffers from mental illness. One notable example occurred in 2011, when a former nurse from Minnesota, William Melchert-Dinkel, was convicted of aiding suicide and sentenced to 360 days in jail. He had used a false identity and communicated with people on a suicide chat room, convincing two (a man from England and a woman from Canada) to kill themselves. This sentence was less than the 15 years maximum, but there were lingering questions about whether, with proper treatment, those young people might have decided to live. Most of the jurisdictions allowing assisted suicide attempt do include safeguards to ensure that the clinical outlook is terminal rather than viewing it solely as a matter of respecting patient autonomy.

**3. Are withholding/withdrawing of treatment similar or different from (physician-) assisted suicide and euthanasia?**

The question relates to the assumption that it might be morally permissible, at least in some cases, to withhold treatment (allowing a person to die), while it is not permissible to take direct action designed to help a patient to die (killing a person). The prohibition of killing (do no harm) is often regarded as an element forming the basic trust between a patient and a physician/health care provider that cannot be easily replaced. In line with the principle of futility presented in the case, clinicians face a difficult challenge; they must consider what is best for the patient, the views of the patient and his/her family, as well as their own beliefs, whether religion-based or otherwise.

**4. What is the role of interest groups in the public policy process? Of the media? Who are the key players concerned with this issue?**

The role of interest groups and the media in the public policy process are discussed in further detail in Chapter 1, sections 4 (Interests) and 5.8 (Role of Media). As presented in the

case, organizations on both sides of this issue are using the attention to further their arguments, and to solicit donations for their respective cause.

**5. What difference would it make if these decisions were made by: legislatures? courts? providers? patients and their families?**

As noted in Chapter 1, section 4.3 (Scope of Conflict), the determination of who makes policy decisions may help determine who is at the table, under what rules, and whose voices prevail. In the courts, for example, decisions are largely focused on the particular individuals involved in that case, and are supposed to be based on interpretation of the relevant legislation. In legislatures, a wider scope of arguments can be heard, but the emphasis is on creating general frameworks. There are also issues about what role government should be playing (see Chapter 1, section 3.2, Role of the State). If decisions are left to providers, one may assume that these professionals are bound by professional values (see Chapter 1, section 6.4, Professionalism) and on expectations of clinical benefit. Patients and families will be more likely to emphasize their personal beliefs. The class may wish to discuss why such intensely personal questions are being debated at all (see Chapter 1, section 5.1, Agenda Setting), and the role of what Stone calls policy stories about individual cases in placing euthanasia onto the policy agenda (Stone, 1989) (see Chapter 1, section 3.4, Framing).

**See also in Chapter 1:**

- 2.2.1 Federalism in Canada: *The Constitution Act, 1867*
- 2.2.2 *Charter of Rights and Freedoms*
- 3.2 Role of the State
- 3.4 Framing
- 3.6 Ethical Frameworks
- 4 Interests
- 4.3 Scope of Conflict
- 5.1 Agenda Setting
- 5.8 Role of Media
- 6.4 Professionalism

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## Chapter 23: Teaching Notes

### Screen Tests: Genetic Testing in the Nursery and the Workplace

*Yvonne Bombard, Marion Byce, Joe T.R. Clarke, Céline Cressman, Rea Devakos, Daniel Farris, Daune MacGregor, Zahava R. S. Rosenberg-Yunger, Natasha Sharpe, and Raisa B. Deber*

#### Outcome

#### Newborn Genetic Screening Example

As a result of the recommendations from Ontario's Advisory Committee on Newborn and Childhood Screening, in 2006, the Ontario Ministry of Health and Long-Term Care (OMOHLTC) decided to expand newborn screening from 2 to 27 diseases; this was subsequently expanded to 29. The two conditions they had already been screening for were phenylketonuria (PKU), the screening success story, which they had been screening for since the mid 1960s, as well as one of the tests mentioned in the case, congenital hypothyroidism, which they had been screening for since 1978. Both were retained on the list of disorders that Ontario would screen for. Of the other four tests mentioned in the case, sickle cell disease and cystic fibrosis (CF) were added; Duchenne muscular dystrophy and Krabbe were not.

Decisions about what other genetic diseases should be tested for, and in which populations, is often left up to the genetics professionals (physicians, academics and researchers). Note that the provincial advisory committees that Ontario had established were usually comprised of medical geneticists, laboratory experts, epidemiologists, hospital administrators, and ethicists; they would meet periodically to establish what they think should or should not be done. The provincial ministry would then examine their recommendations and determine what would be deemed an insured service.

Note that individual clinicians still retain the ability to do other genetic testing when their clinical judgment deems it necessary, although who then pays may be contentious. (Under such circumstances, the testing would probably not be considered screening, since it would be based in part on clinical suspicion that the patient was likely to have a particular condition.) Determining which genetic screening tests will be publicly paid for falls clearly under the jurisdiction of provincial governments; at the time of writing, no national policy existed for population-based genetic screening. Neither did most Canadian provinces, including Ontario, have legislation requiring genetic screening.

Note that the employment example refers to a hypothetical company, and hence does not have a specific outcome.

#### Possible Points for Discussion:

##### *1. What criteria would you use to evaluate the merits of genetic screening programs? What should (or should not) be screened for?*

The issue of genetic testing is linked both to evidence (in terms of the characteristics of the tests, the conditions, and those who might be screened), but also to values as they relate to such emotional issues as quality of life, ethics of abortion, choices, rights of the fetus, and

societal responsibilities versus individual rights. These differing values are also linked to differing ethical implications (Andermann et al., 2010; Kass, 2001; Wilson & Jungner, 1968).

A US task force on newborn screening had recommended screening for 29 primary target conditions, and suggested reporting information on another 25 secondary conditions if and when they were revealed in the screening process. One key point raised in the US analysis related to the difference between screening and diagnosis – in this case, whether the condition could be identified among newborns (24 to 48 hours after birth) at a phase when it would not ordinarily have been clinically detected, and where there were demonstrated benefits of early detection in terms of treatment (Watson et al., 2006). The US task force process assigned scores to each potential test, on a scale where the maximum was 2,100. The cutoff score they used was 1200 (Watson et al., 2006). However, the UK came up with different recommendations. They did use similar criteria, but varied in the cut-off score they used.

For newborn screening, varying recommendations were made between 2005 and 2007 by the US American College of Medical Genetics panel, the UK, Australia, and the Netherlands; these were summarized by Wilson et al. (Wilson et al., 2010). The examples in the case received the following US scores, where the maximum was 2,100, and their cutoff score was 1200 (Watson et al., 2006):

*Congenital hypothyroidism* met the OMOHLTC guidelines for a screening program. A reliable screening test exists, the disease is easily and effectively treatable, the disease is of a high enough prevalence to warrant screening for it, and the implementation of a screening program is cost effective. It was recommended for inclusion in the US, England, Australia, and the Netherlands, and is screened for in all Canadian provinces. This condition received a very high score of 1,718 on the US process, ranking second.

*Sickle cell* is included among the hemoglobinopathies. It was recommended in the US, England, Australia and the Netherlands, but in Canada it is only screened for in BC and Ontario. Note that sickle cell, CF and other diseases that are more prevalent in certain populations present ethical difficulties, such as whether one should offer screening only to those of particular ethnic backgrounds. It received a US score of 1,542.

Although New York State has made testing for *Krabbe disease* mandatory, the Secretary's Advisory Committee on Heritable Diseases in Newborns and Children recommended against adding Krabbe disease. It received a US score of 447, ranking last among the conditions tested for. Duchenne and Becker *muscular dystrophy* also did not make their cutoff, receiving a US score of 776.

Screening newborn infants for *cystic fibrosis* (CF) is controversial. Some argue that it is not clear that there is much benefit from newborn screening for these infants. Burke *et al.* note examples of infants whose genotypes are not normal, but also do not match a clear CF diagnosis; many are likely to remain symptom free, but parents may experience considerable anxiety. (Burke et al., 2011). There are also problems with false positives and results that have unclear clinical significance. It received a US score of 1,200. It was recommended for inclusion in the US, England, Australia, and the Netherlands, and is screened for in BC, Alberta, and Ontario (with Saskatchewan announcing plans to include it).

In practice, there is considerable similarity in the criteria used by different organizations/jurisdictions to evaluate genetic screening programs, but there are also differences in how different groups use and weight these criteria (e.g., parents, clinicians, interest groups, ethics committees, funders, employers, etc.). Groups may also vary in what they believe constitutes sufficient evidence. The criteria may also change over time (Bombard et al., 2009a).



In the United States, no regulations were in place at the time of writing for evaluating the accuracy and reliability of genetic testing. Most genetic tests developed by laboratories were categorized as services, which the US Food and Drug Administration (FDA) did not regulate. Only a few states had established some regulatory guidelines. Recommendations often emphasized such needs as: ensuring privacy and confidentiality and protecting patients from discrimination and stigmatization; fully informed consent for genetic testing; ensuring quality management in laboratory testing; and ensuring that governments and regulatory bodies examine and take steps in the areas of patents, commercial use and direct marketing of genetic testing.

The criteria that the Ontario panel decided should be used in judging whether it would implement a particular screening test for a particular condition/disease were similar to those used for evaluating screening tests (see Chapter 1, section 8.2.1, Criteria for Screening) (Wilson & Jungner, 1968). The panel augmented this by also looking at whether screening should be targeted to particular groups. They suggested using the following considerations: Is there a screening test for the condition? Is the screening test both sensitive and specific? Is there a treatment for the disorder once it has been diagnosed? Should the whole population be screened, or should a particular population be targeted for screening? Is screening for that condition of overall benefit, and acceptable, to the community? Is the implementation of the screening program cost-effective?

Note that this way of asking the question does not clarify how “the community” should be defined. This can be problematic, particularly if a particular disease disproportionately affects particular sub-populations. The Ontario panel added several additional criteria that they felt were particularly applicable to newborn screening, which they described as follows:

*Identify Objective:* The specific reason for genetic screening should be clearly defined (e.g., is the goal medical intervention, reproductive planning, and/or research?)

*Feasibility:* The screening for medical intervention should be carried out in the context of an integrated program. The facilities, resources, and personnel must be available to provide education and counseling for both the population and for participating health professionals regarding the screening test, retrieval of individuals with positive screening tests, diagnostic confirmation, treatment, and evaluation of outcomes.

*Propensity:* High-risk individuals should be detectable by a simple, inexpensive test that has high sensitivity, specificity, and predictive efficiency.

*Significance of Disease:* The condition for which screening is undertaken should be medically significant in the population under consideration.

*Benefit of Treatment:* When the goal of screening is treatment of disease, affected individuals should benefit significantly as a result of any medical intervention initiated on the basis of the screening procedure. Agreement must exist regarding type of treatment and who to treat.

*Consent:* Individuals should be informed of the goals, operation, and implications of the screening program, and they should have the right to refuse testing without prejudice.

*Regulation:* The outcome and impact of any screening program should be monitored and the program modified, if necessary, based on the results of continuing evaluation of its performance.

*Values:* Individual values and rights must be protected.

*Cost:* The cost of the tests is not prohibitive and meets cost-benefit analysis.

The class may wish to discuss several underlying ethical assumptions that may enter into such decisions. These include:

*The Concept of Normality* requires determination of what is normal or abnormal. One concern that has been expressed, if it becomes possible to prevent the birth of “abnormal” children, is the implications for how those living with those abnormalities will be treated. There will always be “defective” children, not to mention those who acquire disabilities later in life. What is defined as normal, and who judges? The discovery of the mechanisms of heredity in the early part of this century had led to the hope that evolution, instead of being left to random selective processes, might be more efficiently manipulated by planning the selection process. The term “eugenics” (meaning good birth) was created in the 1880s by Charles Darwin's cousin Francis Galton, who hoped that this would improve humanity. One ongoing theme in the literature is that the eugenic movement continues to cast a dark shadow. Certainly, selective breeding is used to “improve” animals and plants; its extension to humans is far more controversial, particularly given its association with genocide under the Nazis and forced sterilization in other countries (including the United States and Canada). It became so associated with racist views about which genes were considered “good” (generally, those of white Christians) that the term has become tainted.

The class may wish to discuss the implications of different ethical frameworks (see Chapter 1, section 3.6, Ethical Frameworks). In particular, utilitarianism would stress the moral rightness of human actions in terms of their consequences (i.e., the end justifies the means). In contrast, deontological reasoning evaluates the action by itself, arguing that if an act is inherently wrong, it cannot be morally correct regardless of its consequences. A number of the ethical principles noted in section 3.6 are particularly relevant to this case. The principle of *respect for persons* would argue that individuals should be treated as autonomous agents, and that persons with diminished autonomy are entitled to protection. The principle of *beneficence* would argue that we should do no harm, maximize possible benefits, and minimize possible harms. The principle of *justice* requires that we treat persons fairly and that we give each person what he or she is due or owed. Justice requires a fair sharing of burdens and benefits. Clearly, there is no obvious “correct” policy.

Another ethical issue is how to balance individual vs. societal concerns. One of the central criteria for either population-based or high-risk screening is that it be acceptable to the community involved. One set of objections to screening can be traced to the conflict between the rights of the individual, and the rights of society as a whole. By what standards might society decide that its interests are more important than the freedom of the individual? Many issues tie into this conflict. Compulsory screening of marital partners or parents carries the threat that persons with certain genotypes may not be allowed to marry or have children. Involuntary sterilization (e.g., of the mentally retarded) was sometimes employed, and remains controversial. One way of framing it is whether parents should be allowed to have children that are likely to become the responsibility of the state. Other issues may be worded in terms of “rights”, including the right of the fetus to be born, the right to be born free of genetic defect, the rights of the parents and the rights of society. The good of society may or may not contravene individual rights. These questions have yet to be fully answered, either in the courts, or in public opinion. A related issue is prenatal screening for sex selection in many countries, often linked with the selective abortion of female fetuses. An additional complication arises in multicultural societies, where the views of different subpopulations may vary, particularly if particular conditions are more likely to be associated with certain ethnocultural groups. The balance between societal values and individual freedom is real, immediate, and has profound demographic and ethical implications.

Views of liberty and the role of government are also applicable to discussions about screening (see Chapter 1, sections 3.2, Role of the State, and 3.3.2, Liberty). One view is that individuals should have the maximum latitude to do as they please, subject only to government intervention when their actions interfere with the rights of others. Here, the government would be a neutral observer and become involved only when necessary. This would imply that the government should let the genetics community regulate itself. If government also has some responsibility for the well-being of society (which can be termed paternalistic), then some might argue that they should take on a more active role. An additional complication arises when health care expenditures are considered; to what extent should those paying the bills have a voice? As always, where (and whether) to draw the line is unclear.

In turn, this leads to the question of when it makes sense to screen, including the optimal timing and setting for various conditions and populations. What diseases should be screened for in a community-based public health program, and what should be tested for on an individual, clinically indicated basis? How much technological expertise do you need to screen? To interpret and communicate results? Where do you set the cut-off point as to when a test result is considered to be a positive result? The class may want to discuss the implications of prevalence, incidence, sensitivity, specificity, predictive value, and reliability on testing (see Chapter 1, sections 8.2, 8.2.1, 8.2.2, and 8.2.3). In addition, when is screening for genetic disorders cost-effective? Note the fine line between testing and screening (which depends in part on the extent to which there are other reasons to believe that one might have a particular condition)

One set of issues is balancing the positive and potential negative aspects of genetic testing. Potential downsides may include: a) *test interpretation*. Tests, aimed at healthy people who are identified as being at high risk because of a strong family medical history for the disorder, can be very difficult to interpret. Since many of these diseases are multifactorial, it is often difficult to predict the consequences of the results of genetic testing simply because so many genes and environmental factors may be involved. b) *lack of options to treat*. There can be a long lag time between linking a gene mutation with a disease and developing effective therapies; there is thus a lack of medical options to treat or prevent many of the disorders for which gene tests are used. This raises utilitarian arguments and cost-benefit questions. c) *danger to employment and insurance*. Persons undergoing gene testing may undergo significant risk of jeopardizing their jobs and insurance status. d) *psychological impact*. The psychological impact of testing can be devastating, provoking anxiety over the results, survivor's guilt, fears of discrimination and social stigmatization. Under some circumstances, these factors may be seen to outweigh the benefits of testing.

**2. What should the requirements be for consent to testing in a genetic screening program? Should individuals have the right not to know their status with regard to genetic risk? Should they have the right not to be tested? Should they be encouraged/obligated to share the test results with other family members? Would this differ depending on what treatments are available? Who should have access to the results of genetic screening tests, and under what circumstances? What, if any, provisions should be made for follow-up care and counselling?**

Carrier testing presents additional issues. A carrier is personally healthy, but may give birth to an affected child if the other parent is also a carrier. Ethicists are concerned as to whether other family members should be notified and tested (Burke et al., 2011). In some cases, the community has supported efforts to identify carriers (e.g., Tay-Sachs disease); in others, they

have not (e.g., sickle cell disease). One potentially complicating factor is whether there might be adverse insurance consequences for some of those identified.

Use of the term “right” implies an entitlement, either to receive something (positive rights) or not to be interfered with (negative rights). Free speech, for example, is a negative right, which implies that it is something that no one can interfere with. In contrast, a right to receive health care is a positive right, which implies that someone must provide and finance it. The philosophy literature includes many debates about types of rights, whether these are “natural” (God-given) or merely arise from legislation (in which case they can be taken away). However, expressing something in terms of “rights” immediately moves it into the realm of topics no longer open to debate, which is one reason why such formulations can be contentious. Several issues that arise in the genetic screening context have been framed in terms of “rights.” These include:

*The Right to Remain Ignorant.* Genetic information does not affect only the person who had the test; it often affects other members of his/her family. Who should receive such information? One viewpoint is that all information acquired on a patient or family should be made available to the person/persons concerned, and/or to their guardian if they are not legally competent (e.g., infants, people with dementia). But such information may be damaging. For example, in the course of studying a patient for genetic disease, a clinician may learn that the mother’s husband could not be the child’s father. Should they be informed of that? In the case of autosomally dominant inherited disease, the husband may find it relevant to know that he was not the source of the undesirable allele, but this may also disrupt a functioning family. Huntington disease (HD) is another example where some people may wish to remain ignorant. Because of its relatively late onset in early to late adulthood, normal persons at risk could never be sure that they would not develop the disease, which may result in significant psychological distress. At present it is possible to demonstrate the presence of the HD gene, prenatally or at any time. Should members of HD families or members of the general population be tested for the gene? Some individuals who have discovered that they possess the HD gene have subsequently committed suicide. On the other hand, knowledge that one carries the gene may have a significant impact on decisions to have a family, or on other long-term plans, and knowing that one does not carry the gene may improve peace of mind. A related question is whether testing should be done on individuals, such as children, who are generally judged not to be competent to refuse procedures.

*The Right of Privacy and the Right to Know.* Some may argue that individuals have a right to know genetic information about themselves. If people do not know (as in the case of Huntington disease), childbearing decisions will be based on uncertain information; children may not be born because potential parents who do not have the gene may erroneously fear that they do, and children may be born with the disease when parents hope they lack the disease. Either way, tragedy may occur.

Should genetic information be made available to persons other than the individual concerned? A person’s genotype could be considered to be private medical information, and to make that information available to others may constitute an invasion of privacy. What right do relatives (who may also be at risk) have to genetic information about persons other than themselves? What responsibility does a counselor have to transmit such information to other persons? Should the individual be given such information if that person is not capable of dealing with it? This is particularly complicated for newborn screening, where the information is given to the parents. There are also issues in terms of how (and where) samples should be stored, and

whether secondary uses of the data for research and planning health systems are permissible, and whether this depends on whether the information is or is not linked to an identifiable individual.

Other questions arise from the ability to screen for a genetic predisposition for various cancers such as breast, ovarian, or bowel cancer. This is a key issue in the employee screening example. Some individuals with certain genotypes are more susceptible to developing cancer when exposed to certain environmental agents. Some companies have sought to identify workers who may be especially susceptible for genetic or other reasons, and to remove them from sources of exposure (Geppert & Weiss Roberts, 2007). Is that appropriate? Does a company have a right to screen employees/prospective employees for other genetic traits (for example such traits as alcoholism, manic depression, Alzheimer disease)? These practices could lead to a type of job discrimination where some individuals are denied employment not because of their own work, but because they may develop some sort of occupational illness.

***3. How would your recommendations differ when considering screening for newborns or children? Under what circumstances might the government endorse screening infants for a genetic condition for which there is currently no effective treatment?***

Depending on the condition being screened for, a number of options are possible; these are not mutually exclusive. The best outcome is when treatment exists that prevents the condition from occurring. One classic example is Rh disease, which affects infants where the mother has Rh negative blood type and the father is Rh positive. When the fetus is also Rh positive, the mother often develops anti-Rh antibodies, which cross the placenta and can cause potentially severe, life-threatening hemolytic anemia in subsequent Rh positive offspring before or at birth. However, this can now be easily prevented by giving the woman an anti-RhD IgG immunoglobulin injection during pregnancy or shortly after delivery. As a result of systematic blood group screening and appropriate intervention, the incidence of this condition has been dramatically decreased.

Similarly, screening results can be used to treat affected children to prevent clinical manifestations of disease. As noted in the case, screening at birth for some conditions can allow early detection and early treatment, which can reduce or eliminate severe damage. PKU was the most dramatic example. Congenital hypothyroidism also fits this category; early treatment prevents growth failure and cognitive impairment. Other conditions show less clear benefit from early detection (note also the distinction between screening, and diagnosis after symptoms have appeared). Sickle cell disease is an in-between example; early treatment with antibiotics appears to reduce the risk of sepsis, but such treatment can be slightly delayed (as long as it is given in the first 4 months of life). Detecting cystic fibrosis in newborns, in contrast, does not seem to give any health benefits as compared to later diagnosis. Here, the benefits of testing appear to be in better knowledge rather than in changed therapy (Burke et al., 2011).

A more contentious question arises from using screening results to prevent the birth of affected offspring, which is a contentious ethical issue. For certain conditions, particularly where no therapy is yet available (e.g., Tay-Sachs disease, sickle cell disease, Downs syndroms, and Duchenne muscular dystrophy), one may be able to identify carriers of mutant genes and counsel carrier couples regarding risks to their offspring and the reproductive options available to them. A related, even more controversial possibility is selective termination on the basis of the sex of the fetus (regardless of whether the condition being screened for is present), since this information will also become known in the course of chromosome analyses or other genetic tests done for unrelated diagnostic purposes.

#### ***4. How important is it for jurisdictions to have uniform policies about screening?***

Testing decisions have been affected by changes in technology. Since the 1990s, testing could be done using tandem mass spectrometry, which allowed screeners to measure many compounds, and hence test for many metabolic disorders at the same time. That was the rationale for expert review panels to decide which conditions should be screened for, particularly since many of the disorders that could be detected could not be treated (Watson et al., 2006).

A review of newborn screening policy noted that although such screening occurs in at least 64 countries, there is considerable variation in what is screened for (Wilson et al., 2010).

Arguments for a uniform approach are, in part, based on issues of equity across jurisdictions, and/or on whether there might be economies of scale. Note the differences between non-communicable diseases and public health interventions (see Chapter 7, Looking for Trouble), since, in contrast to communicable diseases, decisions by one jurisdiction not to perform such tests would be unlikely to generate externalities that would affect people in other jurisdictions. Arguments against a uniform approach might include recognition that there would be regional variation, especially since prevalence of conditions often varies across jurisdictions. They also note that there is limited federal constitutional jurisdiction in this area (see Chapter 1, section 2.2.1, Federalism in Canada), particularly if screening is deemed to be a health care program. The federal government might provide funding, but it is unclear whether (or why) it would wish to play a leadership role.

#### ***5. What should the company's policy be? Should insurance companies have the right to require individuals to undergo genetic testing before issuing disability or life insurance? Should they have the right to request the results of previous genetic tests? Should they be able to use information about family history of various diseases? What safeguards may be needed to protect insurance companies from adverse selection? Discuss the similarities and differences between information from family history and information from genetic tests.***

As far as some of the other conditions suggested for the workplace screening example, *Huntington disease* (*Huntington's chorea*) meets some of the OMOHLTC guidelines for screening tests. There is a genetic test for the disease, there is a fairly reliable screening test, but there is no treatment for the disorder once it has been diagnosed. The prevalence of the disease is fairly low so it is doubtful that mass screening for it would be cost-effective. In addition there are significant moral and ethical issues that have to be dealt with in instituting any screening program for a genetic disease of such late onset.

As noted in Chapter 1, section 5.9 (Insurance, Elasticity and Moral Hazard), insurers may seek to exclude individuals at a higher risk of needing care. Note that family history is similar to genetic information, if somewhat less accurate. Indeed, under some circumstances, genetic information can clarify that an individual had not inherited a potentially hazardous gene.

In general, one cannot lie to an insurance company; withholding relevant information can be grounds for cancellation of a policy. However, insurers may also refuse to insure those at high risk of disease. This can result in a Catch-22 situation, in that deliberately not knowing can be the only way of ensuring continued access to insurance. A strong negative is that those individuals may also be denying themselves potentially effective treatment. Family members may also be affected, to the extent that this information could result in similar discrimination against them for being in a high risk category. This is clearly a greater issue when insurance is provided by competitive companies, none of which wishes to have to cover high risks, than when there is a single, universal payer who must cover everyone.

**6. Should workers be required to undergo screening for genetic sensitivity to environmental exposures in the workplace? What is the responsibility of the employer with regard to protection of the health of workers who test negative in such a screening program?**

Note that the United States has passed a number of provisions restricting the use of genetic information and “genetic discrimination” in the workplace, as well as in receiving health insurance.

Employers may think they have a clear interest in genetic information about employees or job applicants. The information of interest might include risk factors for such potentially costly conditions as early-onset Alzheimer, heart disease, cancer, addiction, as well as some psychological traits and sensitivities to chemicals or other workplace contaminants. If the burden of health care costs shifts to the private sector, Canadian employers, like their American counterparts, may become much more interested in hiring only the healthiest employees with the “right” genetic characteristics. At the time of writing, there appeared to be little, if any, genetic testing of employees or job applicants in Canada. However, claims about “genetic discrimination” have been made. It remains unclear the extent to which employers should be able to obtain and use personal genetic information to make decisions about employing individuals and assigning them to certain tasks, and whether human rights provisions against discrimination are adequate to deal with workplace genetic testing. Trade unions have tended to oppose genetic testing for increased individual susceptibility to environmental toxins. Their rationale is not grounded in reasons of privacy or employment discrimination. Rather, they argue that permitting employers to identify and refuse employment to individuals shown by genetic testing to be particularly susceptible to potentially harmful environmental contaminants produced by the company makes it tempting for the employer to allow higher levels of environmental pollution in the workplace than would otherwise be considered permissible. The action of the employer in this situation is based on a threshold concept of the harmful effects of environmental pollution, a concept that unions maintain is seriously flawed, particularly in the case of exposure to ionizing radiation.

**See also in Chapter 1:**

- 2.2.1 Federalism in Canada: *The Constitution Act, 1867*
- 3.2 Role of the State
- 3.3.2 Liberty
- 3.6 Ethical Frameworks
- 5.8 Role of Media
- 5.9 Insurance, Elasticity and Moral Hazard
- 8.1 Economic Analysis: Cost-effectiveness
- 8.2 Screening
  - 8.2.1 Criteria for Screening
  - 8.2.2 Assessing Screening tests (test/truth)
  - 8.2.3 The Role of Prevalence

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## About the contributors

**Raisa B. Deber**, PhD, is a Professor, Institute of Health Policy, Management and Evaluation (HPME), Faculty of Medicine, University of Toronto, Toronto, Ontario. She has lectured, mentored, published and consulted on health policy at local, provincial, national and international levels. Her current research, conducted with colleagues and students, includes examination of the public-private mix in health care financing and delivery (including the implications of the distribution of health expenditures), health human resources, primary health care, issues associated with the movement of care from hospitals to home and community; and approaches to accountability. In 2009 Professor Deber received one of Canada's most prestigious lectureships, the Emmett Hall Memorial Lectureship; it recognizes outstanding contributions to the health ideals articulated by Justice Hall: equity, fairness, justice and efficiency. In 2012, she was elected a fellow of the Canadian Academy of Health Sciences.

**Catherine L. Mah**, MD, FRCPC, PhD is Head of the Food Policy Research Initiative launched by the Ontario Tobacco Research Unit at the Centre for Addiction and Mental Health, and an Assistant Professor in Public Health Policy and Clinical Public Health at the Dalla Lana School of Public Health, University of Toronto. Dr. Mah leads several CIHR-funded projects including a study on ethical reasoning in policy debates on food advertising to children and the framing of policy interventions to address household food insecurity. She is engaged in research partnerships with Toronto Public Health and the Toronto Food Strategy, and is a member of the Toronto Food Policy Council.

These case studies arose from Raisa Deber's graduate course, Case Studies in Canadian Health Policy, in HPME at the University of Toronto. As can be seen, these cases tap a wealth of knowledge and expertise. Most of the students taking the course are mid-career professionals, enrolled in a variety of programs and departments, including MSc/PhD programs, and Master of Health Science (MHSc) professional programs. Most of these cases arose from real life situations the initial case author(s) had encountered that offered generalizable insights, and were further developed in subsequent years in active collaboration with other students who had chosen to present and develop that case. Note that their initial contributions to the cases were in their roles as students, although they were kind enough to read and comment on the revised versions.

Here, briefly, is some information about the co-authors and what they told us that they were doing when they signed off on the revised case, recognizing that in this rapidly changing environment, 'currently' may no longer reflect what they are doing today. Any views expressed do not necessarily reflect the views of their current employers, although (as noted in the acknowledgments), we are gratified by the positive reactions we have received.

**Monica Aggarwal**, PhD, is a health care consultant with extensive experience in: primary care; eHealth; policy development and service design; program and project design, planning and implementation; health services research, analysis and evaluation; and change management. Dr. Aggarwal has a special interest in improving primary and mental health care services for patients through health services research, policy development and management.

**Mohamad Alameddine**, PhD, is currently an assistant professor at the Department of Health Management and Policy at the Faculty of Health Sciences, American University of Beirut (AUB). He joined AUB in 2008, coming from the University of Toronto where he worked as a senior research associate and prior to that as Director of International Development at the Faculty

of Medicine. Mohamad holds a PhD in Health Management and Policy from the University of Toronto and a Masters of Public Health from AUB. His main research interests are focused on studying health human resources labour force dynamics, recruitment and retention practices and the quality of work environments. Mohamad has a number of publications in the field and is regarded as a regional health systems consultant.

**Nurlan Algashov**, MD, MHSc, was born in Almaty, Kazakhstan and completed his MD at the Kazakh National Medical University in 2005. He received the International Presidential Scholarship “Bolashak”, and obtained his MHSc from the University of Toronto in 2008. He worked as an expert-analyst in the health sector in the JSC National Analytical Center under the Government and the National Bank of the Republic of Kazakhstan. After that he worked as a Senior Manager, then as a Director of the Department of Strategy and Analysis at Nazarbayev University in Astana. In 2012 he worked as a Deputy Chairman and then as an Acting Chairman at the Republican Research Center for Emergency Care. Currently he works as a Deputy Chairman at the National Medical Holding.

**Karen Arthurs**, RN, MHSc, has held a variety of management positions in acute care, government, private consulting and community/public health. Currently she is Manager, Infant Children and Youth Services at Vancouver Coastal Health and oversees public health programs for high risk maternity clients and young children in the Vancouver community.

**Marie Balitbit**, MHSc, CHE, DC is currently responsible for regional site operations and business development at one of UHN Altum Health's outpatient rehabilitation facilities. She is also an Administrative Surveyor, traveling frequently to conduct accreditation surveys on rehabilitation organizations in the US on behalf of the Commission on Accreditation of Rehabilitation Facilities (CARF). Previous roles held by Dr. Balitbit include: Director of Quality Management and Evaluation at Centric Health, National Healthcare Program Specialist for the Healthcare Services and Corporate Procurement Departments at Aviva Canada Insurance and independently owned and operated a chiropractic clinic. She is a registered chiropractor, has an MHScs degree from the University of Toronto and holds a Certified Health Executive designation from the Canadian College of Health Leaders.

**Patricia Baranek**, PhD, is currently a health services and policy research consultant in Toronto and has an adjunct appointment as an Assistant Professor in the Institute of Health Policy, Management and Evaluation at the University of Toronto. She has co-authored *First Do No Harm, Evaluating Reform Remedies for Canadian Health Care* (UBC Press, 2002) and *Almost Home: Reforming Home and Community Care in Ontario* (U of T Press, 2004).

**Charles Battershill**, PhD (York University), continues as York University contract faculty in social science and sociology. He specializes in sociology of work, industry, occupations and professions and teaches about economic globalization. He does this while operating a modest financial planning business as a representative of Primerica Financial Services, Inc.

**Andrea Baumann**, RN, PhD is the Associate Vice-President of Global Health at McMaster University and the Scientific Director of the Nursing Health Services Research Unit, funded by the Ontario Ministry of Health and Long-Term Care. She is also a Professor in the School of Nursing, and Director of the World Health Organization Collaborating Centre in Primary Care Nursing and Health Human Resources. Her many publications focus on decision-making and health human resource issues. In addition to her research, she has directed several international projects in relation to capacity building and higher education.

**Sherry Biscope**, MHSc is currently working as a Research Consultant with Toronto Public Health.

**John Blake**, PhD is an Associate Professor in the Department of Industrial Engineering at Dalhousie University in Halifax, Nova Scotia. He received a Bachelor's degree in Industrial Engineering from the University of Toronto in 1988 and a doctorate in IE from the University of Toronto in 1997. John also holds an appointment with Canadian Blood Services' Research and Development Group. John is interested in the application of operational research techniques to problems in health care. These include wait times for medical care, operating room scheduling and operating room time allocation, case mix planning, platelet ordering and inventory analysis, blood product production and distribution, and multi-echelon supply chain management.

**Daniel Bolland**, MHSc, moved from health administration to work for Baxter pharmaceutical company, and then became interested in the software that they used to make, sell, ship and run their books. After working as a consultant with Deloitte, he started his own consulting company, designing & implementing that same software, which is now owned by Oracle. He is now an independent Oracle consultant, working internationally.

**Yvonne Bombard**, PhD received her Interdisciplinary doctorate in Medical Genetics at the University of British Columbia. She completed postdoctoral fellowships at the University of Toronto, Yale University and Memorial Sloan-Kettering Cancer Center. Now a Scientist at Li Ka Shing Knowledge Institute and Assistant Professor at IHPME at the University of Toronto, she conducts policy and health outcomes research in genomics, personalized medicine and health technology assessment.

**Chris Bonnett**, MHSc, is President of H3 Consulting. His expertise is in workplace health strategy, and health policy research, specializing in pharmaceuticals and the private sector. Chris has served as a volunteer Board member for three health service organizations in the community and hospital sectors, and is a member and past Chair of the Canadian Council on Integrated Healthcare. He holds an MHSc from the University of Toronto, and is a PhD candidate in the School of Public Health and Health Systems at the University of Waterloo.

**Maureen Boon**, MHSc, is the Senior Advisor, Executive Office at the College of Physicians and Surgeons of Ontario. Maureen obtained her B.Sc. from Queen's University and M.HSc. from the University of Toronto. She was responsible for developing and managing all College policies for 9 years, most recently as Associate Director, Policy. Her current portfolio includes Strategic Planning, stakeholder relationship management and eHealth project leadership.

**Karen Born** is a PhD candidate in Health Services Research at the Institute of Health Policy, Management and Evaluation at the University of Toronto. She holds an MSc in International Health Policy from the London School of Economics and an Honours BA in Political Science from McGill University.

**Laurie Bourne**, MHSc, is currently the Senior Manager of Access to Care Informatics at Cancer Care Ontario (CCO). Before joining CCO in 2010, Laurie was a consultant at the Courtyard Group healthcare consulting firm in Toronto, from 2007-2010. Previously she also was a health analyst for the Chief Medical Officer of Health (CMOH) at the Ontario Ministry of Health and Long-Term Care. Laurie holds an MHSc in Community Health and Epidemiology and an MHSc in Health Administration from the University of Toronto.

**Talar Boyajian** is a medical student at the University of Toronto, class of 2014. She has an MSc in Health Policy, Management and Evaluation from the University of Toronto and a

Bachelor of Science in Cell Biology from McGill University. She has published research and worked in knowledge translation in the field of high-risk obstetrics.

**Susan Bronskill** is a Scientist at the Institute for Clinical Evaluative Sciences and an Assistant Professor in the Institute of Health Policy, Management and Evaluation at the University of Toronto. She has a PhD in Health Policy from Harvard University and an MSc in Health Administration from the University of Toronto.

**Marion Byce** received her BSc in Biology, University of Guelph, her MHSc Health Administration, University of Toronto, and is a Registered Technologist (Cytogenetics). She presently owns and runs Spiritwood Farm in North Caledon with her husband and three daughters. Marion and her family train and sell show horses, and teach horseback riding.

**Jane-Anne Campbell** worked for many years with incredible children and families, alongside dedicated colleagues, at Holland Bloorview Kids Rehabilitation Hospital in Toronto. She is currently a full-time Mom with three amazing young daughters whom she and her husband Glen adopted from China. She has a passion for the issues affecting children with special needs and their families, and is hoping to resume her PhD studies in this field.

**Heather Chappell, MSc CHE** is the National Director, Cancer Information and International Affairs at the Canadian Cancer Society. In this role she oversees the development of cancer information and national/international cancer control strategic partnerships. She has a BSc in Kinesiology from the University of Western Ontario, an MSc in Health Policy from the University of Toronto, and is a Certified Health Executive with the Canadian College of Health Leaders.

**Rachna Chaudhary** has practiced as an occupational therapist in Ontario for 9 years, primarily working with children with varying special needs in the non-profit sector (e.g., children's treatment centres). She received her BSc (OT) from Queen's University in Kingston, ON, and her MHSc from Health Policy, Management and Evaluation (HPME) at the University of Toronto in 2011. Rachna has recently been selected to the Board of Directors at the Scarborough Centre for Healthy Communities (SCHC), a not-for-profit community health centre (CHC) in the Greater Toronto Area, that services at risk and marginalized populations. Rachna is passionate about evidence based healthcare, the twelve determinants of health, children's health, positive organization culture and using an ethical and system's level approach to ameliorate the Canadian healthcare system.

**Munaza Chaudhry** is an independent health research consultant who has worked with federal and provincial governments, universities and not-for-profit organizations in the areas of chronic disease management, primary health care and quality improvement. She is currently completing her PhD in Health Policy, Management and Evaluation at the University of Toronto.

**Carole-Anne Chiasson, MHSc, OT Reg. (Ont.)** has worked at Holland Bloorview Kids Rehabilitation Hospital for nine years; her titles have included occupational therapist, manager, project support and quality analyst. She is passionate about quality in healthcare, and about her family.

**Joe T.R. Clarke, MD, PhD, MSc, FRCPC, FCCMG.** Currently Professor Emeritus, University of Toronto (Dept of Pediatrics), Professeur d'enseignement clinique, University of Sherbrooke (Quebec), and Past Chairman of the Provincial Advisory Committee on Maternal-Childhood Screening (Ontario). He is the sole author of three editions of *A Clinical Guide to Inherited Metabolic Diseases* (Cambridge University Press) first published in 1996, and of over 180 papers published in peer-reviewed medical scientific journals.

**Kathryn Clarke**, MHSc, RD, is currently working as a consulting dietitian in long-term care.

**Andrea Cortinois**, PhD, has worked as a journalist, a researcher, a teacher, and a manager of health-related interventions on four continents, mainly in low-income countries. Born in Italy, he earned a Masters of Public Health from the University of Wales College of Medicine, Cardiff, UK, and a PhD from Health Policy, Management and Evaluation at the University of Toronto. Andrea works at the Centre for Global eHealth Innovation, Toronto General Hospital, where he leads the Multiculturalism and Health research stream within the People, Health Equity and Innovation (PHI) Research Group. He is an Assistant Professor at the Dalla Lana School of Public Health, University of Toronto, and teaches courses on migration and health and international health. His current research focuses on the application of new information and communication technologies to reach marginalized population groups.

**Maria Isabella (Marisa) Creatore**, PhD is the Manager of the Health Database Research Initiative and an epidemiologist at the Centre for Research on Inner City Health (CRICH) at St. Michael's Hospital and the Institute for Clinical Evaluative Sciences (ICES). She has an MSc in epidemiology at Queen's University (2000) and a PhD from the University of Toronto (2013).

**Céline Cressman** is a PhD student in the Institute of Health Policy, Management and Evaluation at the University of Toronto. Her academic background includes an MSc in Public Health Research from the University of Edinburgh, and a degree in Social Studies of Medicine from McGill University. Her PhD thesis seeks to examine the structures of decision-making and organization of service delivery in child health screening policy.

**Ian Dawe**, MD, MHSc, is the Physician-in-Chief at Ontario Shores Centre for Mental Health Sciences and an Associate Professor and Head of the Division of General Psychiatry, Department of Psychiatry, University of Toronto.

**Doreen Day** is a Senior Project Manager with the Ontario Provincial Council for Maternal and Child Health. She has completed an Honours BSc from McMaster University, an MHSc in Health Administration from the University of Toronto and holds the qualification of Certified Health Executive (CHE) from the Canadian College of Health Leaders.

**Rea Devakos** works in digital publishing and archiving, and most importantly, is the liaison librarian for the University of Toronto's Institute of Health Policy, Management and Evaluation. She holds an MLIS from UBC and an MHSc from the U of T.

**Rinku Dhaliwal** graduated from McMaster University in 2002 with her BSc in Nursing. Her interest in mental health led her to specialize in Child and Adolescent Psychiatry as a Registered Nurse in an acute care hospital in the Waterloo Wellington LHIN. She obtained her MHSc from the University of Toronto in 2011, and is now focusing her career on developing strategies to support health system integration across the continuum of care.

**Sarah Mullally Dimmock** currently works at Women's College Hospital in Toronto, where she directs strategic projects in areas of Quality Improvement and Patient Safety. As a clinical Occupational Therapist, Sarah specialized in neonatal intensive care and acute care pediatrics at The Hospital for Sick Children in Toronto. Sarah completed her MHSc in Health Administration at the University of Toronto, BHSc in Occupational Therapy at McMaster University, and a BA (Hons) in Political Science and History at McMaster University.

**Mark Dobrow**, PhD, is Director, Analysis and Reporting, Health Council of Canada and Associate Professor in the Institute of Health Policy, Management and Evaluation at the University of Toronto. Previously, he was Scientist and Lead of the Cancer Services & Policy

Research Unit at Cancer Care Ontario. Dr. Dobrow's areas of research interest focus on optimizing the use of scientific and non-scientific evidence, performance management systems and clinical/corporate accountability mechanisms to support/guide decision-making by organizations that manage, organize, finance and/or deliver health services.

**Adam M. Dukelow** MD, MHSc, FRCP(C), CHE is an Associate Professor in the Division of Emergency Medicine at the University of Western Ontario. Dr. Dukelow's clinical practice is based at London Health Sciences Centre (University and Victoria Hospital Emergency Departments) and St. Joseph's Health Centre (London) Urgent Care Centre. Dr. Dukelow has a special interest in improving patient care through health administration.

**Laura Esmail**, PhD is a Senior Manager at AcademyHealth (Washington, DC) where she helps lead projects on patient and stakeholder engagement, patient-centered outcomes research and comparative effectiveness research. She obtained her doctorate in pharmaceutical policy from the University of Toronto and has over 10 years of experience in the design, analysis, and dissemination of research that aims to improve patient outcomes and health policy.

**Sheryl Farrar** BSc, MHSc has worked in the fields of primary health care, hospital relationships with primary health care providers, and public health. She is currently a program manager in public health in Eastern Ontario.

**Daniel Farris** completed studies in Biology and joined the Canadian Forces in 1985. He has completed a Certificate in Health Services Management from the Canadian Healthcare Association and an MHSc from the University of Toronto. He is a CHE and is also a graduate of the Canadian Forces Staff School and Land Forces Command and Staff School.

**David Ford** is a management consultant with healthcare consulting experience in London and Toronto. He previously worked with the Ontario Medical Association as a Senior Policy Analyst and holds an MHSc from the University of Toronto.

**Brenda Gamble** received her PhD in Medical Sciences from the University of Toronto and is an Assistant Professor in the Faculty of Health Sciences at the University of Ontario Institute of Technology (UOIT). Her research areas include health human resources, accountability in healthcare, interprofessional practice and the medical laboratory sector.

**Stephanie Gan**, following graduation from the University of Toronto, entered the ranks of the Canadian federal public service through the Accelerated Economist Training Program and is currently an analyst at the Privy Council Office.

**Katerina Gapanenko**, MD, PhD, received her MHSc in Health Administration at the University of Toronto, HPME, Faculty of Medicine.

**Michael Gardam**, MD, Director of Infection Prevention and Control at the University Health Network (since 2001), and former Director of Infectious Disease Prevention and Control at the Ontario Agency for Health Protection and Promotion (2008 - 2010), is devoted to discovering and uncovering new ways to prevent the spread of infectious diseases in healthcare settings and the community. He continues to champion the elimination of 'superbugs' as Physician Director of the Community and Hospital Infection Control Association Canada (CHICA) and the National Lead of the "Stop Infections Now!" collaborative for Safer Healthcare Now!, and to run the tuberculosis (TB) clinic that he founded in 2000 at Toronto Western Hospital. He is an expert consultant (internationally) on patient and staff safety issues such as TB, SARS, pandemic influenza, medical device reprocessing and hospital superbugs. Michael is also an Associate Professor of Medicine at the University of Toronto. Michael is a graduate of McGill University in Montréal and the University of Toronto and is a Fellow of the Royal College of Physicians and Surgeons of Canada in infectious diseases.



**Nada Victoria Ghandour** is the Statutory Specialist at the Region of Peel for the last several years. She has graduated with a Masters in Public Administration and Policy at Carleton University. She currently serves as the vice chair on the Municipal Education and Research Fund, and currently sits on the Access and Privacy Working group at the Association of Municipal Clerks and Treasurers of Ontario. Nada is working towards an Information Access and Privacy Protection certificate at the University of Alberta and continues to focus her research on access to information and privacy as it relates to municipal government administration.

**Erin Gilbert, PhD**, is an independent healthcare consultant with expertise in performance measurement, quality improvement and the application of evidence-based clinical practice guidelines with an emphasis on the aging population. Recent work includes data analysis and report writing for a longitudinal study of assisted living and long-term care residents in Alberta. Her clients include academic institutions, government and health care providers.

**Asmita Gillani**, is the CEO, Aga Khan University Hospital, Nairobi, Kenya (AKUH,N). She came to AKUH, Nairobi from York Central Hospital in Richmond Hill, Ontario, Canada, where she served as Chief Operating Officer for more than seven years and as CEO for six months before she was called upon to assume her current position. Ms Gillani holds an MHSc from the University of Toronto and a BSc (Hons) from the University of London, England. She is a Certified Health Care Executive with the Canadian College of Health Care Executives. She has received awards for her professionalism and volunteerism (including the Queens Golden Jubilee Award), published articles related to the health profession and served on important Canadian health committees. Her contribution as a volunteer has been extensive, including Chair of the Aga Khan Social Welfare Board for Canada and as Vice President of the Aga Khan Council for Canada for two consecutive terms. Currently Ms Gillani serves on many public-private committees dedicated to furthering the quality and standards of care in the region.

**Joanne Greco** is the Vice President, Infrastructure and Chief Nursing Officer at Closing the Gap Healthcare Group. As a passionate health care leader who has repeatedly demonstrated her ability to provide leadership excellence in community healthcare, Joanne has over 20 years of experience in various leadership roles at such organizations as the Toronto Central Community Care Access Centre (Director of Client Services) and the former North York Community Care Access Centre in Toronto. Some of Joanne's work experiences include leadership in various reviews and projects to improve health system processes and efficiencies, involving primary care, acute care, long term care, and community care sectors. She holds a BSc in Nursing from the University of Windsor, and an MHSc in Health Administration, University of Toronto. Joanne also has certificates in Project Management, Lean process improvement and is a Certified Health Services Executive.

**Shawna Gutfreund** holds an MA in Philosophy with a Specialization in Bioethics from McGill University and an MHSc in Health Administration from the University of Toronto. She has worked as a research ethics coordinator, privacy officer, and policy analyst.

**Olivia Hagemeyer** completed the MHSc Health Administration in 2009. She is a Speech-Language Pathologist and Manager of the Augmentative Communication & Writing Aids Program at Surrey Place Centre in Toronto, ON.

**Carrie-Lynn Haines** is a Registered Nurse who has had experience in a variety of roles over the past thirty years including Emergency Department administrator, change agent, investigator, clinician, educator, consultant, and patient care advocate; having worked in a variety of healthcare environments including Academic/Tertiary and Community Hospitals, Public Health, the College of Physicians and Surgeons of Ontario and the Ontario Hospital

Association. She is currently Project Manager, Ontario at the Canadian Patient Safety Institute. Carrie graduated with an MHSc degree in Health Administration from the University of Toronto in June 2011.

**David Hoff** worked for 20 years for the Ontario Ministry of Health and Long-Term Care in a variety of director level positions in policy and planning. He worked as a Public Member of the Consent and Capacity Board, and of the Ontario College of Pharmacists, and works with the Canadian Coast Guard Auxiliary. He has masters degrees in philosophy (U.W.O) and public health (University of Michigan) and has also done graduate studies in health policy (University of Toronto) and epidemiology (U.W.O.).

**Jeff Hohenkerk** is currently Vice President of Quinte Health Care in Ontario. Jeff has 28 years of experience, both in the public and private health care sector. His experience includes Medical Diagnostic Imaging, Laboratory Services, Strategy, Clinical Informatics, Capital Redevelopment, Performance Management, and Transformation. Jeff played a major role as a Provincial MRI Process Improvement Coach for the MOHLTC and Vice Chair of the Wait Times Strategy and Diagnostics Working Group to improve wait times for the province. He was also an active member of the CE LHIN Regional Rehab Working Group, the Clinical Education Leadership Council of the Michener Institute for Applied Sciences, the Breast Screening Program for Rouge Valley Hospital and volunteers as a board member on several non for profit organizations. He holds a Masters in Health Administration, Lean Six Sigma Black Belt Certification, Bachelor of Applied Sciences, Diploma of Health Services Management and a Medical Radiation Technology Licence. Jeff is a Certified Health Services Executive.

**Julie Holmes** is currently the Director of Ambulatory Services at St. Joseph's Healthcare in Hamilton, Ontario. She has a BA degree from McMaster University and an MHSc degree from the University of Toronto.

**Paul Holyoke** has a PhD in Health Policy from the University of Toronto, a MSc (Econ) from the London School of Economics and a law degree from the University of Toronto. He is Saint Elizabeth Health Care's Director of Research and Program Development, and he teaches at York University's School of Health Policy and Management. Paul's current areas of research are personal support and rehabilitation services in home care and education programs and supports for unpaid family caregivers.

**Lisa Jackson**, MHSc, is a health care administrator with a broad range of skills in strategic planning, general management, and consulting. Lisa has varied career experience including working in three countries (Canada, United States, and Scotland). Lisa has particular expertise in implementing complex change management initiatives that span the continuum of care.

**Carolina Jimenez**, MD, MSc was born in Bogota, Colombia. She did an elective in the Department of General Surgery at the University of Toronto and a research elective at the Centre for Global eHealth Innovation as a med student. After moving to Canada, she completed a master's degree from the Institute of Health Policy, Management and Evaluation, under the supervision of Dr. Alex Jadad. Her thesis was a systematic review and content analysis of national ICT and eHealth policies in Latin America and the Caribbean. She has continued doing research at the University of Toronto and the University Health Network.

**David Kirsch** is a research fellow in the Global Health Diplomacy Program at the Munk School of Global Affairs. He has masters level degrees in computer science and health policy, and a PhD in medical science. He has a keen interest in healthcare and the public sector and is committed to improving program effectiveness through sensibly applied accountability and

governance. His current research interests include accountability, governance, under-5 mortality and innovation. He advises governments and major businesses in the areas of strategic planning, business transformation, enterprise architecture, informatics, program evaluation, accountability and governance.

**Joshua Kline, MD** is a practicing family physician with Parkview Physicians Group and the Physician Leader of the Primary Care Service Line, Parkview Health, Fort Wayne, Indiana. He worked on this case while studying at the University of Toronto on a Fulbright scholarship.

**Christopher A. Klinger, PhD** received his PhD in the Institute of Health Policy, Management and Evaluation (HPME) at the University of Toronto. After working as a long-term care nurse in Germany, he developed a passion for improving care for this population. He has also studied at the Research Summer School at Lancaster University's International Observatory on End of Life Care in the United Kingdom, worked for the National Hospice and Palliative Care Organization, Inc. (NHPCO) in Virginia, and taught health systems courses at Fachhochschule Koblenz. He currently holds a research assistantship with the Bruyère Research Institute's (BRI) Palliative Care Education and Research Program in Ottawa, with: the National Initiative for the Care of the Elderly's (NICE) End-of-Life Issues Theme Team.

**Irene Koo** currently works as Quality Lead in Ambulatory Programs at SickKids Hospital. Prior to completing her MHSc she worked as a physical therapist for over ten years specializing in rehabilitation of children with neurological disorders. She has taught courses at George Brown College and University of Toronto. Her interests are in looking at system efficiencies that allow a more seamless transition for families navigating the health care system.

**William Kou, MHSc**, is an epidemiologist at the York Region Community & Health Services Department in Ontario. Mr. Kou has worked on various projects including population health assessment reports, the development of a balanced scorecard for public health and an ongoing risk factor surveillance survey for adults.

**Nancy Kraetschmer, MBA, PhD**, is a senior healthcare leader with extensive experience in health policy, research and evaluation, and strategy. Dr. Kraetschmer's research interests include hospital accountability and performance measurement systems. In addition to her day job, she also holds an Adjunct Faculty position in the Institute of Health Policy, Management and Evaluation at the University of Toronto.

**Seija K. Kromm** holds a MA in economics from the University of Calgary and is currently a PhD candidate at the Institute of Health Policy, Management and Evaluation at the University of Toronto. Prior to her PhD studies, she worked as a Laboratory Technician in the area of fertility evaluation and treatment, and as a Research Associate in health economics.

**Kerry Kuluski** completed her PhD in Health Services Research at the University of Toronto in 2010. Following this she spent 6 months as a Visiting Scholar with the Health Experiences Research Group at the University of Oxford. Kerry is currently a Research Scientist at Bridgepoint Health in Toronto, Ontario Canada where she is leading a program of research on complex chronic disease and patient experience.

**Lise Labrecque, BSW, MHSc, Cert Prog Eval.**, is an evaluator and health promoter working in Ottawa, Ontario. She currently works in the Public Health sector, supporting management teams with strategy implementation and leadership development. Before going to Public Health, Lise spent 15 years developing, implementing and evaluating community-based health promotion programs in Community Health Centres.

**Kenneth Cheak Kwan Lam, PhD** is a Course Director in the School of Health Policy and Management and Adjunct Professor in the Graduate Program in Health at York University.

Kenneth previously worked as a consultant with the OMHLTC and in various capacities with the Ontario Agency for Health Protection and Promotion (now renamed Public Health Ontario), The Change Foundation, and the Ontario Hospital Association. In addition to his doctorate in health policy from the University of Toronto, he also holds an Honours Bachelor of Arts with distinction in Political Science from the University of Toronto, a Master of Arts in Political Science from McMaster University, and a Master of Public Administration from the School of Policy Studies at Queen's University. Commencing in Fall 2013, Kenneth will be pursuing the Master of Studies in Law at the University of Toronto while continuing with his teaching at York.

**Bev Lever**, BA, MSW, MHSc in Bioethics, PhD candidate has worked in Executive positions in the public, private and health research sectors. Her experience as the Vice-President, Provincial Government Relations/Stakeholder Partnerships with Canada's Research-Based Pharmaceutical Companies as well as her position as Lead, Health Care Research for the Ontario Ministry of Health and Long-Term Care positioned her well to address pharmaceutical/health care issues in a fair and ethical manner.

**Leah Levesque**, BScN, MHSc, CHE is the Vice President of Patient/Resident Services at the Arnprior and District Memorial Hospital and the Grove Nursing Home. Leah has worked in a variety of clinical settings including critical care as a nurse and later, managed departments including Emergency, Medicine/Surgery, Operating Room, and PACU in both the rural and urban settings. Leah completed her Masters in Health Administration at University of Toronto in 2010.

**Esther Levy**, MHSc, has held a variety of management and policy positions in health care and with the Ontario government. Formerly a Speech-Language Pathologist in neuro-rehabilitation, she worked with the Ministry of the Attorney General's Office of the Public Guardian and Trustee on the operationalization of health consent and substitute decision making legislation. Within the Ministry of Children and Youth Services she led a number of key policy and program initiatives in child welfare, and is currently the Director of the Child and Youth Development Branch.

**Judy Litwack-Goldman**, MHSc, President of Judy Litwack-Goldman Consulting, has extensive experience in strategic planning, capacity assessments, board development, fundraising and communications for non-profit and charitable organizations. Since 1990 she has been helping non profit organizations and charities adapt to change.

**Christopher J. Longo**, PhD is Associate Professor, DeGroote School of Business, Health Policy and Management, & Member, Centre for Health Economics and Policy Analysis, McMaster University, and Associate Professor (status only), Dalla Lana School of Public Health, University of Toronto. He holds a BA in Economics, York University, MSc, Physiology, University of Western Ontario, and PhD, Health Policy, Management and Evaluation, University of Toronto. Dr. Longo has over 20 years of industry and academic experience in clinical research, economic evaluation, and market access and policy strategies for pharmaceuticals. His research interests include: the economic and quality of life evaluation of health technologies (predominately pharmaceuticals) in the areas of cancer, diabetes, sepsis, and public health programs; the equity implications of efficiency initiatives on patients' financial burden for health care; global pharmaceutical pricing strategies; and behavioral factors that lead to higher individual consumption of health care resources. Although still involved in many research projects related to the healthcare system and its end users, he has refocused his research agenda.

His latest research examines the costs and economic evaluation of interventions/programs throughout the cancer journey, with the intent of informing policy decision making.

**Helen Looker** has worked in several fields of research since graduating from U. of T. in 2005, including seeking best practices for injury prevention, and as an interviewer for a McMaster University stroke rehabilitation study that compared costs of institutional versus home delivery of services. Currently, as a MSc in Planning graduate, Helen is acquiring technical skills for a career in the Planning profession and looks forward to planning healthy communities.

**Nibal Lubbad, MD, CCFP, MHSc**, is currently working as a family doctor in Burlington, Ontario – a specialty she has so much passion for. Born in Gaza, Palestine, Dr. Lubbad went to Russia for her MD, graduated from St. Petersburg Academy of Medicine, and worked as a general practitioner in Palestine. In 2003, Dr. Lubbad completed her MHSc in Family & Community Medicine, University of Toronto, and also received her Academic Fellowship in Family Medicine from that department. After working as a research officer in Health Policy, Management and Evaluation, University of Toronto, including studies of the impact of primary health care on the acute care sector, she completed her Family Medicine Residency at McMaster University, Department of Family Medicine, Hamilton, Ontario.

**Daune MacGregor, MD** is a Paediatric Neurologist and recently completed two terms as Associate Paediatrician-in-Chief, and Associate Chair, Clinical Services, in the Department of Paediatrics at the Hospital for Sick Children, University of Toronto. Her most recent appointment is as Associate Medical Director, SickKids International. She completed her medical training at the University of Saskatchewan graduating cum laude in 1971. She then trained in Paediatrics and Neurology in Toronto at the Hospital for Sick Children and did postgraduate studies in Developmental Neurology at the Hospital for Sick Children, Great Ormond Street, London, England and the Children's Hospital Medical Center at Harvard University in Boston, Massachusetts. She was appointed a Full Professor of Paediatrics and Neurology at the University of Toronto in 1995. Her research interests are in the study of cerebral vascular disorders including stroke and headache, and neurodevelopmental disorders including acquired brain injury in children. Dr. MacGregor is a Past President of the Canadian Association of Child Neurologists. She is currently completing MBA studies at Athabaska University.

**Leslie MacMillan, MD, MHSc** is a hospital clinical associate in Medical Oncology in Toronto.

**Maria Mathews, PhD** is an Associate Professor of Health Policy/Health Care Delivery in the Division of Community Health & Humanities, Faculty of Medicine, Memorial University, Nfld. She has a PhD in Health Policy, Management and Evaluation from the University of Toronto and a Masters in Health Services Administration from the University of Alberta.

**Mina Mawani, MHSc**, is the Chief Development Officer at the Greater Toronto CivicAction Alliance (CivicAction), leading the organization's resource development and capacity-building strategies. Prior to joining CivicAction, Mina was CEO of the Aga Khan Council for Canada, and has also held key roles at the Ministry of Health and Long-Term Care, KPMG, and PricewaterhouseCoopers, working with the largest hospitals in Ontario. Mina has a talent for building consensus on tough decisions, and uses her business background and strong financial and analytical skills to ensure that a compelling vision is backed by a solid business plan.

**Elizabeth McCarthy, RSW, MHSc CHE** has worked in the Ontario health care system for the past twenty-five years, most of it in hospital leadership positions. During a five-year

period working as a consultant in a Ministry of Health and Long-Term Care regional office, she gained perspective on how local needs and interests are able to influence public health policy at a provincial level.

**Christopher W. McDougall** holds a BA and an MA in political science from McGill University, was a graduate student at the Institut de sciences politiques de Paris, and a visiting fellow at the Erasmus Mundus Master of Bioethics at the Università degli Studi di Padova. He is currently completing a doctorate in health policy and bioethics at the University of Toronto's IHPME. Christopher's research lies at the intersection of international law and relations, population health, and moral theory. His recent publications have focused on ethical and public health arguments for improving infectious disease control policy, multilevel health governance, and global health diplomacy and assistance. Christopher was also part of a three-year project at NCCHPP and the INSPQ to develop a wide array of tools and resources for the integration of moral reasoning into the everyday practice of Canadian public health professionals.

Major **Brandy McKenna** is a Regular Force Military Health Care Administrator who has been serving with the Canadian Forces since 1996. Her numerous appointments have included administrative, operational, and clinical roles, both domestic and abroad. Brandy's career highlight includes being deployed to the Role 3 Multinational Medical Unit (combat hospital) in Kandahar, Afghanistan for a seven month rotation (August 2007-March 2008) as the National Medical Liaison Officer/Administrative Officer. Having graduated from the Royal Military College of Canada (Kingston, Ontario) with an undergraduate degree in Honours English (2000), she also completed a Health Management Certificate Program through Ryerson University, Toronto (2003), achieved her Certified Health Executive (CHE) certification through the Canadian College of Health Leaders (2004), and completed an MHSc Health Administration through the University of Toronto (2011). Brandy is currently the Officer Commanding/ Clinic Manager for 2 Field Ambulance Medical Clinic at Garrison Petawawa.

**Meghan McMahon** is a PhD student in the Institute of Health Policy, Management and Evaluation at the University of Toronto. Her research interests centre on health care financing and funding. She is also the Assistant Director of the CIHR Institute of Health Services and Policy Research.

**Wendy Medved** is a graduate of the MHSc Health Administration program in Health Policy, Management and Evaluation at the University of Toronto. She has a background in sociology, and has extensive research and project management experience, having conducted and coordinated numerous socio-behavioural, epidemiological, and clinical research studies on health-related issues. In 1994 she conducted a qualitative research study on the socio-psychological impact of in vitro fertilization treatment failure on childless women. She is currently a Policy Lead at the Health Council of Canada.

**Elaine Meertens** received her MHSc from the Health Administration program at the University of Toronto. A nurse with experience as a clinical manager, she is currently the Director, Cancer Planning and Regional Program Development at Cancer Care Ontario.

**Paul Miller**, MD, MHSc, FRCPC, is a staff Emergency Physician at Hamilton Health Sciences Centre and an Assistant Clinical Professor of Medicine and Pediatrics (Divisions of Emergency Medicine) at McMaster University in Hamilton, Ontario. His academic interests include administrative medicine, systems improvement and physician engagement.

**Gunita Mitera**, BSc, MRT(T), MBA, PhD Candidate, is a Quality Initiatives Specialist at the Canadian Partnership Against Cancer in Toronto, Ontario. She previously worked as a Radiation Therapist at the Sunnybrook Odette Cancer Centre. Her research interests include

health services research related to access to care, health policy, palliative care, and health technology assessment.

**Lucinda Montizambert** holds an MHSc (Health Promotion) from the University of Toronto and a MA in International Affairs from the Norman Patterson School of International Affairs at Carleton University. Lucinda currently works as a senior policy analyst at Status of Women Canada and is a member of the Society for International Development Board of Directors, Ottawa Gatineau and chairs its Gender Working Group.

**Frances Morton-Chang**, MHSc, is currently a PhD. candidate in Health Policy at the University of Toronto, where she pursues her keen interest in gerontology and health policy; her thesis examines the mix of resources required to maintain frail and/or cognitively impaired seniors (deemed eligible for LTC facility placement) safely in the community. Her work experience spans a variety of health sectors, including homecare, acute-care, long-term care, and charities, with a specialty in the area of dementia (particularly Alzheimer disease). Frances is also a sought-after consultant with Local Health Integration Networks, NGOs, private and not-for profit organizations, and a doting mother to two beautiful sons.

**Shaheena Mukhi**, MHSc, is a flex-time PhD candidate in Health Policy, who works at the Canadian Institute for Health Information (CIHI). At CIHI, she is leading the development and implementation of the pan-Canadian Primary Health Care Voluntary Reporting System and comparative reports to improve access, availability and use of primary health care information for quality improvement and health system evaluation and planning.

**Michèle Parent**, MSc, PhD is an Aboriginal health scholar currently working as a consultant. She formerly taught at Nipissing University School of Nursing and the Faculty of Nursing, University of Regina. She is Métis and an active member of the Canadian College of Health Leaders.

**Allie Peckham** is a PhD student in the Institute of Health Policy Management and Evaluation at the University of Toronto. Allie graduated from the University of Toronto in January 2009 with a Master of Social Work. Prior to her studies at the University of Toronto Allie completed her BA, Honours Gerontology, Minor Sociology at McMaster University. During her studies she has gained considerable experience in conducting both qualitative and quantitative research related to care for seniors and their informal caregivers in the home and community care sector.

**Yeesha Poon**, BSc,Phm, MBA, MSc,HTA, PhD (Candidate), worked as a Drug Advertising Reviewer at Advertising Standards Canada and is now Director of Market Access, responsible for drug formulary submissions across Canada with Ferring Inc.

**Caroline Rafferty**, MHSc, is a healthcare executive, graduate of the HPME program and Registered Nurse. She has a broad range of work experiences within the public and private healthcare sectors. Caroline has worked in the development of public health policy that includes hospital funding, service integration and EMR development. As a senior healthcare consultant, she has provided leadership for initiatives in a variety of healthcare sectors, nationally and internationally, to address cost, quality and access pressures. Currently, Caroline is focused on primary care reform, where she continues to pursue her passion of public policy implementation to improve access and system integration for the benefit of individuals and their families.

**Glen Randall** is an Associate Professor in the Health Services Management area of the DeGroote School of Business and Member of the Centre for Health Economics and Policy Analysis at McMaster University. He holds a PhD in Health Policy, Management and Evaluation from the University of Toronto, as well as a MBA, MA, and BA from McMaster University.

Professor Randall's research interests focus on the impact of health care policies on health professionals.

**Natalie (Wajs) Rashkovan**, MHSc, is currently working as a Program and Project Manager for the University of Toronto Stroke Program (UTSP). The ability to exercise her research and project management skills over a broad range of health-related areas is what keeps her energized and loving her work.

**Melissa Rausch** is the Manager of Business Development and Special Projects at SRT Med-Staff in Toronto. Melissa received her MHSc in Health Administration from the University of Toronto.

**David Reeleder** graduated in 2006 with his PhD in Health Policy and Bioethics from the University of Toronto. After over 20 years with the Ontario Ministry of Health and Long-Term Care performing a variety of policy related managerial portfolios, he currently operates as an independent health care consultant.

**Zahava R. S. Rosenberg-Yunger**, PhD is currently a postdoctoral fellow at the Keenan Research Centre of the Li Ka Shing Knowledge Institute of St. Michael's Hospital. She obtained her PhD from Health Policy, Management and Evaluation and the Collaborative Program in Bioethics at the University of Toronto. She completed a MA in Interdisciplinary Studies at York University. Dr. Rosenberg-Yunger's research interests include health studies research, ethics, priority setting, health policy, and mixed methods designs.

**Eleanor Ross**, BScN, MScN, has been President of the professional associations in Ontario (RNAO) 1987-89, Canada (CNA) 1994-96, and Vice-President of the International Nurses (ICN) 2001-05. Her nursing practice has included teaching, research, clinical nurse practitioner and administration. A number of awards and honours have been bestowed on her.

**Mark Rovere** is a Senior Policy Advisor in the Health System Strategy and Policy Division at the Ontario Ministry of Health and Long-Term Care. Mr. Rovere was previously Associate Director (2010 to 2012) and Senior Policy Analyst (2006 to 2010) in the health policy research centre at the Fraser Institute. He holds an Honours Bachelor's degree and a Master's Degree in Political Science from the University of Windsor, and is currently completing a Ph.D. in Health Services Research (health policy) at the University of Toronto's Institute of Health Policy, Management and Evaluation (IHPME). He has authored and co-authored numerous studies, articles and commentaries on a wide-range of health and pharmaceutical policy related issues.

**David Rudoler** is a doctoral candidate in the Institute of Health Policy, Management and Evaluation at the University of Toronto. Before pursuing his doctoral degree, David received a Master of Public Policy Administration and Law from York University. David also has experience working in a number of departments in the Ontario Public Service, including senior level positions within the Ontario Ministry of Health and Long-Term Care.

**Somayeh Sadat**, PhD, University of Toronto, is a health care consultant experienced in population-based and clinical service analyses in support of health system planning, as well as process reengineering in support of quality improvement initiatives.

**Miriam Alton Scharf**, BScN, MHSc had an extensive career in health care, working in community health, acute care teaching hospitals and community based organizations. In her management role in a multidisciplinary setting, she developed new programs, and evaluated current programs focusing on goals and results based management. Sadly, she passed away in June, 2012.



**Brian Schwartz, MD** is an associate professor in the Department of Family and Community Medicine and the Dalla Lana School of Public Health at the University of Toronto, and currently serves as Chief, Emergency Preparedness and Executive Lead, Service Integration at Public Health Ontario. His academic interests are in health emergency management policy and practice, emergency medical services and critical incident stress in health emergency responders. Dr. Schwartz is the recipient of awards of excellence from the Ontario Medical Association, the Ontario College of Family Physicians and the National Association of Emergency Medical Services Physicians

**Natasha Sharpe** is the President of Bridging Finance Inc. Prior to joining Bridging Finance, Natasha was the Chief Credit Officer for Sun Life Financial's \$110 billion global portfolio. Prior to that, Natasha spent over 10 years at Bank of Montreal where she led various teams in risk assessment and corporate finance. In 2010, Natasha was named as one of Canada's top 40 under 40. Natasha is a director of public, private, and non-profit companies. She holds a PhD in health policy, and a MBA from the University of Toronto.

**Shannon L Sibbald, PhD** is Adjunct Faculty in the School of Health Studies, Faculty of Health Sciences at the University of Western Ontario. She completed her Masters and Doctoral degrees through the Department of Health Policy Management and Evaluation and the Collaborative Program in Bioethics at the University of Toronto. Her research interests include the management and translation of knowledge in various health settings (including primary, acute and public health), health policy/health services research, and the ethics of resource allocation.

**Shahzad Siddiqui** is a Toronto-based lawyer. He is a graduate of the University of Toronto, where he designed an undergraduate program in health policy and did master's level courses with Dr. Deber, before completing an LL.B at Osgoode Hall Law School and an LL.M at the University of Pennsylvania Law School. He has lived and worked in Zambia, England, Pakistan, China, Canada and the United States.

**Louise Signal, PhD**, is a Director of the Health Promotion and Policy Research Unit at the University of Otago, Wellington, New Zealand. Louise has over 20 years experience in health research and practice, including as an advisor to the New Zealand Ministry of Health.

**Rena Singer-Gordon** graduated from the MHSc Health Promotion program at the University of Toronto in 1996. Currently, her company, Holistic Health Matters, specializes in bio-energetic healing solutions for body, mind, and soul. She lives in Thornhill, ON with her husband, Stanley Gordon.

**Joe Slack** is a Technical Specialist in the Performance Measurement Department at University Health Network. Joe completed his MHSc - Health Administration at the University of Toronto and is a Certified Health Executive.

**Karen Spalding** is the Director of the Graduate Program in the Daphne Cockwell School of Nursing, Ryerson University, Toronto, Ontario. As a paediatric nurse with a PhD focusing on health policy, the main focus of Dr. Spalding's research program is examining the role of government in health care, how it is shaped by the interests and actions of key political actors and professional organizations; and the consequences of health system changes for health care organizations, providers (nurses), consumers (parents and children) and governments themselves. Dr. Spalding is currently co-investigator on several externally funded research studies that involve both quantitative and qualitative methods that study the delivery and organization of paediatric home care. As a nurse and health policy researcher Dr. Spalding is committed to

ensuring that the new knowledge generated through her research is translated to key decision makers, consumers, providers and government policy makers.

**Carolyn Steele Gray**, PhD received her degree at the University of Toronto in Health Policy, Management and Evaluation in 2013. Her doctoral work focused on accountability in the home and community care sector in Ontario. She is working as a post-doctoral fellow at the Bridgepoint Collaboratory for Research and Innovation in Toronto. The post-doctoral work focuses on developing and implementing integrated care plans for complex continuing care patients and creating electronic patient reported outcomes tools. She holds an MA in Public Policy and Administration from Ryerson University where her work focused on performance measurement in supportive housing. In addition to her studies, Carolyn worked as a program evaluator for the York Institute for Health Research, Program Evaluation Unit, and has been involved in a number of health services research projects.

**Wendy Sutton** is a Toronto lawyer with an LLM in health law, and is a Vice Chair of the Workplace Safety and Insurance Appeals Tribunal. She was a member of the Interim Regulatory Council on Midwifery (Ontario) from 1989 to 1992 and President of the Toronto Birth Centre from 1990 to 2010. Wendy is the co-author with Marilou McPhedran of *Preventing Sexual Abuse of Patients: A legal guide for health care professionals* (2004).

**Phyllis Tanaka**, MSc (Nutritional Sciences), is a dietitian and the Vice-President, Scientific & Regulatory Affairs for Food & Consumer Products of Canada, an association that represents food and consumer goods manufacturers in Canada. Phyllis works specifically on policy and regulatory issues related to the nutrition, food – health paradigm. She is a member of Equal Voice, a non-profit organization with a mandate to change the political scene in Canada so that more women engage in and take political office at all levels of government. Phyllis resides in Toronto ON.

**Vera Ingrid Tarman**, MD MSc FCFP, CASAM is currently the Medical Director of Renascent, and Staff Consultant for the Homestead, Salvation Army.

**Lee Tasker**, BS, PhD received her Bachelor of Science in Kinesiology and Exercise Science (University of Waterloo) and her PhD in the interdisciplinary graduate program at the University of Calgary. Her research examined how the design of a motor vehicle accident insurance compensation system affects access to benefits for claimants who have sustained a traumatic brain injury, and how this, in turn, affects recovery, if at all. She is president of Lee Tasker Counselling Inc.

**Dan Tassie** graduated with a MScPI from the University of Toronto. He currently works as a research analyst at Ryerson University in Toronto.

**Fern Teplitsky** is an experienced educator, planner and facilitator. She has a Bachelor's Degree in Community Nursing and a Masters Degree in Environmental Studies (specialization in Policy and Planning for the Elderly in Ontario). For nine years she was Senior Health Planner with the Toronto District Health Council, where she specialized in planning issues related to seniors, community services, and long-term care facilities. Since 2003 she has operated her own consulting firm.

**Romy Joseph Thomas**, MBA, MHSc, CHE, is a Health Care Executive with special interest in health policy, organizational strategy and operations. Romy's prior assignments include consulting and in the near past serving as COO of an academic health center in India. He has since moved to Toronto and now works for a health service organization in capital planning.

**Kenneth Van Wyk**, MBA, is a practising psychotherapist and the Executive Director of Christian Counselling Services. He is a PhD candidate at the Institute for Christian Studies in a conjoint program with the Free University of Amsterdam.

**Sharon Vanin**, MHSc, works as Legal Counsel at Cancer Care Ontario. She is a graduate of Queen's University, Osgoode Hall Law School, and the University of Toronto.

**Judy Verbeeten**, MD, MHSC, is a retired eye physician and surgeon who practiced in Toronto for 30 years.

**Jillian Watkins**, BSc, is a doctoral student in Health Policy, Management and Evaluation at the University of Toronto. Jillian's doctoral research focuses on the provision of home and community care services for marginalized seniors, specifically seniors who identify as lesbian, gay, bisexual and transgender.

**Anne Wojtak** MHSc, BSc is the Senior Director, Performance Management and Accountability for the Toronto Central Community Care Access Centre. Anne's diverse portfolio includes corporate performance, procurement and contract management, strategic planning, risk management, research, and communications. She is an adjunct faculty member of the University of Toronto in the Health Policy, Management and Evaluation Program where she is a guest lecturer on Strategic Planning and a tutor for Canada's Health System and Health Policy course.

**Rachel Wortzman** is a resident in the Department of Family and Community Medicine at the University of Toronto. Her professional interests include primary care reform, social determinants of health, and healthy public policy. Dr. Wortzman also received her MD and MPH from the University of Toronto..

**Betty Wu-Lawrence**, RN, BscN, MEd, PHCNP, is currently working as a public health nurse with Toronto Public Health. Among her many voluntary and community activities, she was an appointed Council member for the College of Midwives of Ontario, 1993-96.

**Linda Gail Young** served as the Director of Personnel at the Fort McMurray Region Hospital, Alberta, and the Director of Human Resources then Vice-President Human Resources at the Surrey Memorial Hospital. After obtaining her MHSc (Health Administration) at the University of Toronto, she was Vice-President of Medical Operations for the Regina Health District. She passed away far too young and we miss her. Her husband, Dr. Eric Young, wrote that Linda would have been delighted to hear that a second edition of the Case Studies book is being published, especially with her case study in it.

**Debra Zelisko** obtained her Masters degree in Audiology at Western University and has worked over twenty years in hearing health care, in a variety of roles including clinical research, clinical practice, industry, as well as management. She is currently Vice President of Operations at Lifestyle Hearing Corporation. She is also completing her PhD in Health Policy at the University of Toronto.