

Bringing the Public Back In: Stem Cell Research and National Bioethics
Committees as Mechanisms of Public Deliberation

Lucie Marisa Bucci

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Abstract

Bringing the Public Back In: Stem Cell Research and National Bioethics

Committees as Mechanisms of Public Deliberation

Lucie Marisa Bucci

Recently, some scholars have identified a relationship between the building of public credibility and the idea of “public science”- putting more public in policymaking. Some scholars have also found that major players in this relationship are national bioethics committees who seem to act as “mechanisms” of public deliberation. Moreover, these findings have led to the belief that creating a national dialogue is more than just a task incorporated into the normal functions of national bioethics committees; it is a primary duty. There are however some scholars who disagree with this understanding of national bioethics committees. The so-called failures of the President’s Council on Bioethics (PCBE) and the Canadian Biotechnology Advisory Committee (CBAC) to foster national debates on stem cell research brings into question several things, firstly, what place does the public have in science policy? And second, how do reputable advisory committees claim to bridge the gap between science policy and the general public? What I intend to show in this thesis is that national bioethics committees have become numerous and have grown to become significantly important to the policy process. However, their role as “mechanisms” of public deliberation is limited by several factors. These factors or variables include but are not exclusive to: 1) the political environment; 2) institutional independence; and 3) participation technique.

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When I began preparing for this final step in my studies, I realized that this endeavour would require endurance and patience. At that moment, I realized that I had neither, and that I would have to somehow get the strength I needed to succeed from the people around me. For this reason, I want to thank my husband and best friend, Kyriakos, for having faith in me, and for all his patience. My mother, Louise and aunts Rosa and Angela for constantly reminding me how far I've come, and lastly, Professor Francesca Scala, my thesis advisor, for her guidance.

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Chapter 1

National Bioethics Committees, Public Deliberation and the Regulation of Stem Cell Research

1.1 Introduction

The first major discoveries in genetics were believed to be the beginning of a very promising future for biomedical research. Each discovery presented new information about the building blocks of life, and promising cures to perhaps combat late onset diseases like Parkinson's, Alzheimer's or diabetes, which still have no known cure. However, prior to what is recognized as the genetics revolution, research efforts were focused on providing reproductive options for infertile couples. Somewhere in the evolution of reproductive science a connection was made with medicine and genetics research. A leading authority, writing 15 years ago, found that the practice of *in vitro fertilization* (IVF) fell into three distinct developmental periods: "exploration, consolidation, and expansion".¹

The exploration period culminated in the birth of the first test tube baby Louise Brown; the consolidation period lasted until 1989, followed by the "expanded IVF" period of today, which features new technological wrinkles: egg, sperm, and embryo freezing; gamete donation by parties other than the married couple; IVF as a transaction between homosexual couples, surrogate motherhood and genetic diagnosis of embryos.² It is in this latter period, the current period that reproductive research has made a connection with genetics. Nowhere is this truer than with stem cells research where cells are derived from the germinal ridge of embryos or aborted fetuses, which have the capability of regenerating many human cells found in organs such as lungs and heart.³

Today, scientists have discovered several ways to extract stem cells from human embryos. For example, human embryonic stem cells can be obtained from fetuses that are nine-weeks old and have been donated for research after abortion,⁴ or through *in vitro fertilization*. The idea has been to use *in vitro fertilization* as a way to obtain unwanted or abandoned frozen embryos after IVF treatments. Another method involves a procedure called “therapeutic cloning” or “somatic cell nuclear transfer”. Although it has yet to be accomplished, in theory, somatic cell nuclear transfer could recreate human embryos from which embryonic stem cells can be removed by fusing a somatic cell with an enucleated oocyte.⁵ Scientists have also used the parthenogenesis method to obtain human embryonic stem cells. In it, chemicals are used to stimulate eggs to develop into embryos, whereupon these embryos divide until they form blastocysts from whose inner cell mass stem cells can be extracted.⁶ Another source that offers an abundance of stem cells is the umbilical cord blood.

Characteristically, human embryonic stem cells hold much interest because of their pluripotency, that is, their capacity to give rise to the various specialized cells of the body- and because of their longevity, given their ability to be propagated for many generations in laboratory culture without losing their pluripotency.⁷ Until now, these cells have been obtainable only from living human embryos [at the 100-to-200-cell (blastocyst) stage of development] by a process that necessarily destroys the embryos and that therefore make this research morally and ethically controversial.⁸

Stem cell research is praised to have unlimited possibilities and potential benefits, but the science has nevertheless been accompanied by broad public debate on the ethical, moral, and legal implications, since the derivation of stem cells involves the destruction

of human embryos. The idea of destroying human embryos in order to extract pluripotent stem cells challenges the legal notion of what is “human” and the ethical principle of “right to life”. The status of the human embryo is an important aspect that has been central to the debate, but there are also other issues such as problems of informed consent since all eggs, sperms and embryos used in this research usually come from participants of in vitro fertilization (IVF) or abortion clinics.⁹ Given the source of stem cells, discussions have also prompted government involvement because of the challenges to religious, cultural and moral worldviews. Stem cell discoveries have also generated heated political discussions about when and what to regulate and where to draw the lines on what procedures scientists should be allowed to pursue.¹⁰ According to Laurie Zoloth, Director of the Center for Bioethics, Science and Society and Professor of Medical Ethics and Humanities at Northwestern University, “[the stem cell research] debate has served as the great simile in several crucial medical ethics controversies, [and as] a litmus test for our collective understanding of women, sex, faith, and death.”¹¹

In 2004, these ethical, moral, and legal concerns became reality when South Korean scientist and stem cell researcher Woo Suk Hwang claimed to have successfully created 11 stem cell lines by using fresh donated eggs. He also claimed in a paper published in *Science* that the very same cell lines were used to clone an Afghan dog. The embryos created by Hwang and his team were supposedly genetic clones of existing embryos donated by anonymous donors. This event turned the stem cell research community on its head, and led to an open inquiry into Hwang’s claims. A peer review committee later revealed that Hwang used more donor eggs in his study than originally claimed. Moreover, many of the cloned stem cell lines were found to be fake. In fact,

there were allegations that the eggs used in the study were donated by two junior researchers from Hwang's laboratory. This raised serious ethical concerns particularly with regards to whether the women in question received compensation for their eggs, and whether they had consented to the use of their eggs for research purposes.

This scandal validated many concerns held by ethicists, lawyers, advocacy groups, science journalists, and the general public. It also led to a manifestation of the complicated socio-ethical issues at the political level, in local communities, and interest organisations where the responsibility of safeguarding individuals as well as the wider community from the potential risks of science weighs heavily. Regulating the use of human embryos for research purposes has always been an obvious option for policymakers, but for the scientific and business communities the regulation of technology goes against the "right" to scientific freedom and exploration. Governments have therefore called upon experts to form national bioethics committees and advisory bodies that develop policy advice on how to ensure that researchers do not obtain human embryos via unethical methods, and to weigh the benefits and risks of such groundbreaking technologies. The knowledge and experience of experts make them ideal professionals to deal with such issues and engage with concerned citizens.

1.2 Deliberative Politics: "Doing Ethical Deliberation in the Public Sphere"?

In the U.S., the newest national bioethics committee¹² to address the ethical, legal and social issues associated with stem cell research is the President's Council on Bioethics (PCBE). At the time of the PCBE's creation, the newly elected conservative government of President George W. Bush was pressured to address the use of public

funds for stem cell research. Many called for an outright ban, but the president opted to seek external advice. Not long after the president's election to office, the PCBE was mandated with the job to address this debate. In the years to come, the Council published three important documents on stem cell research: *Human Cloning and Human Dignity* (2002), *Monitoring Stem Cell Research* (2004), and *Alternative Sources of Human Pluripotent Stem Cells* (2005). During the preparation stages of these reports, the Council heard countless testimonies during their efforts to provide citizens with a forum to engage in a wider public debate on stem cell research.

However, current discourse on stem cell research reveals that there is a divide between how scholars and journalists felt about the way the PCBE investigated the benefits and risks of publicly funded stem cell research using human embryonic lines. Journalists in particular sensed that the PCBE, although constrained by the Federal Advisory Committee Act (FACA) to have a public dimension in its deliberations, had done a poor job at including the general public in its discussions. Many claimed that the Council marginalized certain perspectives and came short in realizing a national debate on stem cell research. Moreover, its recommendation for a four-year moratorium raised very few eyebrows and faded into the background not long after its release. This stimulated accusations that the White House stacked the committee, and its work accomplished nothing more than window dressing for the President's policy, which was made public and implemented a year prior to the release of the Council's report. Not long after the Council finished its second report on stem cells did its own members criticise the Council's approach to the stem cell research issue and its chair Dr. Leon Kass.

At the same time in Canada, the Canadian Biotechnology Advisory Committee (CBAC) also examined the stem cell research question. Although its mandate clearly emphasized the importance of public deliberation and engagement with the Canadian public on topics of national importance, CBAC supposedly failed to include Canadians in final deliberations. In fact, many Canadians felt that the stem cell issue never reached the level of debate as witnessed in other countries such as the United States. Many attribute this lack of debate to the monopolization of discussions by Canadian experts.

The so-called failures of the PCBE and CBAC to properly consider public views are interesting cases, because they bring into question several things. Firstly, what place does the public have in science policy? And second, how do reputable advisory committees claim to bridge the gap between science policy and the general public? These case studies are also instrumental to this study because they show how national bioethics committees function within different political structures – the parliamentary system in Canada and the presidential system in the U.S. - and reveal that while almost all modern day national bioethics committees are mandated with the task of deliberating with the general public, not all committees are successful at fostering public deliberation.

Recently, some scholars have identified a relationship between national bioethics committees and the building of “public science”- putting more public in policymaking. Some scholars have also found that national bioethics committees act as “mechanisms” of public deliberation in this relationship. These findings have led to the belief that creating a national dialogue is more than just a task incorporated into the normal functions of national bioethics committees; it is a primary duty. There are however some scholars who disagree with this understanding of national bioethics committees. For example, Summer

Johnson in a recent publication criticizes this perspective for placing too much emphasis on the capacity of national bioethics committees to act as deliberative institutions, and relying too much on this understanding to substantiate a set of evaluative criteria.

Yet scholars such as Dzur and Levin have had much support for their view that public deliberation should be considered the primary function of national bioethics committees, and that they should solely be evaluated based on their attempt to engage with the general public. Their reasoning is that bioethics committees empower the general public by raising awareness about issues of national importance and by providing the general public with opportunities to learn about and discuss technical issues, while building public support for policy decisions. According to these scholars, national bioethics committees have undoubtedly encouraged public deliberation long before national discourses were deemed important to the policy process. A short history of national advisory committees reveals that these committees have been vital institutions in western governments for the longest time. For example, there is evidence of some of the earliest form of advisory committees during the presidency of George Washington.

It is important to explain at the very outset of this study that I do not in any way suggest in this thesis that public deliberation is the primary role of national bioethics committees. This generalization made by scholars has created a misunderstanding about the relationship between national bioethics committees and public deliberation. I do not disagree with the notion that public deliberation enhances science policy advising by allowing citizens and experts alike to discuss what is best for society as a whole. Public deliberation not only provides citizens with an opportunity for enlightenment on extremely complex issues, but also offers citizens a chance to rebuild a connection with

their government and with other citizens. What I intend to show here is that national bioethics committees have become numerous and have grown to become significantly important to the policy process. However, their role as “mechanisms” of public deliberation is limited by several factors. These factors or variables include but are not exclusive to: 1) the political environment; 2) institutional independence; and 3) participation technique.

The political environments in both the U.S. and Canada seemed favourable to encouraging public deliberation on the stem cell research controversy. However, as events unfolded the potential to open a national dialogue seemed very unrealistic. In fact, in the U.S., much attention was on the dispute between conservative and liberal perspectives. In Canada, debates remained at political and expert levels while Health Canada prepared draft legislation for the regulation and oversight of stem cell research in Canada. In both countries, the political and ideological environments had an impact on public deliberation.

The failures of the PCBE and CBAC, however, do not rest on the political environments alone. There is also the issue of independence. Both the PCBE and CBAC are closely tied to other governmental institutions and executive branches of government. This has raised considerable scrutiny for the PCBE and to some extent CBAC, and coupled with the participation techniques used by both committees to engage with stakeholders on the stem cell issue leads to the possibility that public deliberation was hindered from the very start.

Drawing from an ideal model of public deliberation proposed by deliberative theorists, and focusing on a comparative approach, this study examines the failures of the

PCBE and CBAC to raise national debates on the ethical, legal, and social issues associated with stem cell research. This thesis has acquired information that will lead toward a greater understanding about the relationship between national bioethics committees and public deliberation. It will also provide insight into the role of the public in science policy making; making this study timely and important if we wish to add to our understanding of society and its relationship with public policy.

1.3 From Public Understanding of Science to “Public Science”

The first theme addressed in this thesis is that of “public science”. Much of the idea behind “public science” stems from public scepticism about past biotechnology policy choices (i.e. genetically modified foods) and the supposed failure of experts to represent the ethical, moral and social values in the risk/benefit evaluation of genetic and genomic technologies has raised questions about the efficacy of expert driven policy. This failure, along with the continual interplay of political agendas, and the possible misuse of scientific information has led to public distrust in expert advisers, prompting a movement for more “public” in science policy making by placing a greater emphasis on better public deliberation processes and more governmental openness.

Research into ‘bringing the public’ back into the policy realm has become a focal point for scholars from a range of backgrounds including bioethics, law, ethics and philosophy. From this research, it has become clear that the potential consequences of stem cell research have pitted various religious and cultural worldviews against one another, and generated political pressure adhering to governments and their decisions. Moreover, there is evidence that suggests that over the past 25 years public protests

challenging expert advice have been on the rise in western societies.¹³ Arguably, these occurrences are believed by some scholars to be connected to feelings of betrayal by governments and experts who have been accused of withholding scientific information that could affect the lives of people worldwide.^{14,15} Some scholars also believe that these feelings of betrayal are related to the fact that citizens are now more knowledgeable than before, and that expert advice does not reflect public needs and wants. What is interesting about this growing population of citizen “experts” is that they too want a place in science policy-making.

However, the literature on the public understanding of science reveals that there are many scholars who have reservations about including citizens in science policy, especially since genomics and genetics generate complex social, ethical and legal implications. Many argue that the current citizenry does not meet the level of understanding required to be able to follow and participate in a discussion of a highly technical nature. In fact, the required level of understanding has been debated for some time. For example, some scholars such as Jon D. Miller argue that a scientifically literate citizen is one who has a general understanding of science and a general vocabulary of scientific terms. By contrast, Shamos argues that a standard of understanding should reflect those of undergraduate physics students, which is a level attainable and necessary.¹⁶

Recently, there have been interesting developments with regards to public understanding of science in most industrialized nations. Most nations have acknowledged a need for a more scientifically literate citizenry, and have placed a greater emphasis on science in adolescent and adult education. It is believed that initiatives like this have had an impact on the public understanding of science, and that it is in the common interest of

both science and the public that the latter know more about science. This view is closely related to the approach of the deficit model. According to the deficit model, scientists are knowledgeable experts and the public are ignorant lay people, and the key task is to arrange better communication and dissemination strategies between scientists and citizens.¹⁷

However, there are several problems with the deficit model. Firstly, it appears to privilege scientists while emphasising one-way communication from experts to lay people. Secondly, it assumes that lay people have no general understanding of science. A series of relatively recent American, European, Canadian and Japanese studies which examine scientific literacy within major urban cities recently show that approximately 17 per cent of adults qualified as being scientifically literate by the end of the twentieth century.¹⁸ This proportion now shows to have doubled since the initial multi-city study.¹⁹ Many scholars attribute the rise in the public's ability to understand science to the new media, which has become a huge part of public culture. According to a study by Benjamin Bates, the average American spends about 7.5 hours each day consuming media products such as newspapers or watching a TV or listening to the radio. By tuning in to these sources of information, it is believed that lay people are able to learn about science and develop a general understanding of the potential ethical, moral and social implications.²⁰

In recent years, this increase in public scientific knowledge has contributed to a growing interest in what is known as the deliberative model of public engagement. Simply stated, this model places emphasis on the relationship between science and the general public.²¹ The roots of this deliberative model can be traced back to the public

interest movements of the 1960s and 1970s, and to the critique of the traditional positivist approach to policy studies, which focused on attempts to apply the lessons and procedures of the natural sciences to social settings by trying to extract and codify universal laws and their responding behaviours.²² This kind of knowledge, according to positivists, is only generated via empirical, objective hypothesis testing of rigorously formulated causal generalizations.²³

Post-positivists challenge this approach and in general reject the promise of scientific fact for predicting social behaviour. Instead it emphasizes a more qualitative view of the policy sciences by focusing on historical and sociological observations about the nature of scientific practices.²⁴ Moreover, post-positivists believe that there is much in science that involves social judgements as Frank Fisher further explains,

“A contemporary school of social science that attempts to combine the disclosures of social and political theory with the rigor of modern science. It calls for a marriage of scientific knowledge with interpretive and philosophical knowledge about norms and values.”²⁵

In this respect, post-positivists argue that crucial debates in politics emanate not over empirical data but through deliberations that produce new understandings of human affairs.²⁶

Lasswell first started this debate when he introduced the ‘policy science of democracy’.²⁷ With this concept, Lasswell was the first scholar to discern a need for the policy sciences to ‘democratize society’. For Lasswell, this involved the strengthening of democracy and its values by involving the views of those who will be affected by the proposed public policies through a participatory process.²⁸ To do this, Lasswell proposed a paradigm that sees the subjective side of social phenomenon. In this way, the policy

sciences can distance itself from cost-benefit analyses and rigid empirical research, and move toward adopting a more democratic approach that aims to preserve human dignity.

Over the past fifteen years, policy theorists have had a renewed interest in deliberative democracy, which presupposes a plurality of views within society, and that citizens hold their own ideals and interests. Public discourse is seen as a means of problem solving, because the basis of democratic legitimacy is rooted in deliberation among citizens.²⁹ It allows people to justify their political positions, personal ideals and convictions through dialogue and transforms political preferences into reasoned views. Public participation is also believed to be an enlightening experience for those who participate.³⁰ As an excerpt from Iris Marion Young's work explains:

“Through a process of public discussion with a plurality of differently opinioned and situated others, people often gain new information, learn of different experiences of their collective problems, or find that their own initial opinions are founded on prejudice or ignorance, or that they have misunderstood the relation of their own interests to others.”³¹

Public deliberation is therefore beneficial in many ways. The first argument for public deliberation is that it promotes citizen education. In this view the benefits of public participation in public affairs include the improvement of moral, practical, and intellectual qualities of those who participate as it makes citizens aware and open to other perspectives.³² Public deliberation also has community-generating power. For example, citizens can become aware of, and consolidate, co-membership in a collective form of life by way of the practices of public reasoning with other citizens who owe their identities to the same values and traditions.³³

Ideally, public deliberation involves mutual respect for others and their views. This means that there is a lot to gain from people agreeing to disagree. Respect for each

others liberties and opinions is what Gutmann and Thompson call reciprocity, a principle which aims to seek fair terms of social cooperation for citizens aspiring for a kind of political reasoning that is mutually justifiable.³⁴ In other words, in a pluralistic society reaching a consensus or agreement on a particular issue may be impossible, but through deliberation, citizens can learn to listen to one another and have respect for different views. Joshua Cohen further explains that, “the notion of deliberative democracy is rooted in the intuitive ideal of a democratic association in which the justification of the terms and conditions of association proceeds through public argument and reasoning among equals”.³⁵ Moreover, Cohen argues that public deliberation is, “[A] kind of institutionalized process of reason giving distinguished by its openness, universal and fair access to political institutions - a strong condition of inclusion, which makes political access independent of social position or natural endowment.”³⁶ Finally, public deliberation encourages “critical” rationality by working to maximize the knowledge of citizens.³⁷

With time the idea of the deliberative model has grown to include new dimensions such as engaging with the general public via consensus conferences, public forums, and even Internet forums. Today, the range of public participation techniques have grown and continue to grow as accounted by a recent American study, which describes that 18% of public bodies have used citizen juries, 47% have commissioned focus groups and 45% have undertaken some form of community planning.³⁸ In this account, the deliberation model provides a structure for citizens to intelligently discuss their moral beliefs and values about issues of concern to society. Therefore, unlike the deficit model which privileges formal knowledge as the key to the relationship between science and the

public, the deliberative model sees a wider range of factors, including knowledge, values, and relationships of power and trust, as having an important part to play.³⁹ In other words, decision making is argued to be grounded in a substantial process of public deliberation, wherein arguments for and against laws and policies are given in terms of whether they advance the common good of citizens and the justice of the political society.⁴⁰

1.4 Public Bioethics: National Advisory Committees and Councils

The second theme addressed in this thesis is that of public bioethics. Despite their commonality, the academic literature on advisory committees is surprisingly limited. In 1975, Thomas Wolamin performed one of the first major studies on presidential committees. He found that all committees are created to fulfill one of three general purposes: analyse a specific problem; create a forum in which a problem is discussed and debated; and manage issues.⁴¹ He also found that advisory committees have unique characteristics, such as:

“[They] always have ‘technical experts’; they are representative of the major interests or areas of knowledge involved in the issue; they are prestigious because of its members who are usually the most ‘eminent’ individuals with high statuses; they are visible when they treat a problem; they are usually created on a *ad hoc* basis; and independent of governmental institutions and objective in their analysis.”⁴²

History also shows that *ad hoc* committees have been used very frequently, and according to Alan L. Dean, this trend is due to the fact that there are many advantages to creating *ad hoc* committees versus longstanding committees. For example, *ad hoc* committees have the capacity to focus public attention on a particular problem; they are independent from government agencies and institutions; they have the ability to represent

diverse interests and points of view; they are effective at enlisting persons with national reputations and competence; they have the ability to collect and publish important information; they can stall precipitate government action; and they are effective at placing public pressure for governmental action.⁴³ In addition to these advantages, scholars have identified several types of committees that reflect these functions.

For example, Wolanin demarcates four types of advisory commissions: 1) crisis commissions which usually emerge upon demands resulting from a national crisis; 2) policy analysis commissions to analyze policy; 3) issue/avoidance commissions which are purposely used with the intent to distract the public from the problem at hand, and finally 4) window dressing commissions which support policy decisions made by government by not challenging them. According to Wolanin committees are not expected to make radical changes in the political, economic, and social order.⁴⁴ They are expected to make proposals for ameliorating the status quo. This means that what committees suggest are not always accepted or given much attention. In fact for Wolanin, it is not uncommon or even out of the ordinary for committees to be used as window dressing for what governments have decided to do or not to do.

Wolanin is the first of many scholars to develop a typology of national advisory committees. Much of what Wolanin emphasizes in his work is re-visited by Graham⁴⁵, Zegart⁴⁶, and Flitner. What is interesting to note with regards to all types of advisory commissions or committees is that they are all designed to restore public credibility and confidence in governmental institutions including the policy making process. Government actors have more than often taken advantage of this legitimizing function. One activity that has notably been the route to better legitimacy is public education.

Many scholars have observed the ability of advisory committees to have an educational impact in various social contexts. They have the ability to educate the general public by setting discursive agendas and concept articulation. They also have the ability to connect with professional communities and to educate their own colleagues, and they have the power to change the intellectual perspectives of government actors (although this may not always be the case).⁴⁷ As former U.S. Supreme Court Justice Felix Frankfurter⁴⁸ observed, “Commissions are admirable means for taking the nation to school. This ability is the product of the publicity they can generate for a problem and for their proposal to solve it, the increased impact that their findings and recommendations have because of the prestige of the commission and the higher legitimacy attached to proposals.”⁴⁹ Advisory committees have therefore, according to this discourse, become essential in raising public awareness on specific social issues and starting national deliberations.

1.5 The Stem Cell Research Controversy: the President’s Council on Bioethics and the Canadian Biotechnology Advisory Committee

Today, ‘public science’ and public bioethics converge on many social and political levels. Many scholars, however, agree that it was the stem cell research controversy that officially merged the two. The debate that emerged reveals in many ways that science is indeed public and that citizens have a right to know about its implications. In the U.S., the very question of “killing” human life for research has created the deepest moral divide which is often compared to the 1973 decision by the U.S. Supreme Court in the *Roe v. Wade* trial, which legalized access to abortions until fetal viability. This decision by the US Supreme Court was not widely accepted, and in

response to public concerns raised by the passage of this decision, the U.S. Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (NCPHS).⁵⁰ The Commission proposed a principal of equality of treatment for fetuses brought to term and those aborted.⁵¹ In 1978, the Commission published the Belmont Report, a document that identified ethical principles applicable to research on human subjects, which supported its initial statement.⁵²

Between the 1970s and the 1990s, many other advisory bodies examined the issue of using human embryos for research. For example, the first committee to suggest that research on embryos should be allowed was The Ethics Advisory Board (EAB) of the U.S. Department of Health, Education, and Welfare. It suggested that with the consent of gamete providers, remaining embryos from IVF (*in vitro* fertilization) treatments could be frozen, discarded, or donated to others for research.⁵³ However, the U.S. Congress did not agree with the recommendations of the committee and initiated a fifteen-year ban on research using human embryos.

In 1998, this debate was re-ignited when biomedical researchers successfully isolated pluripotent stem cells forcing former President Clinton to seek advice from the recently formed National Bioethics Advisory Commission (NBAC) to investigate the issue.⁵⁴ NBAC reported that federal funds should be made available for research, however, the fact remains that any policy permitting public funding for stem cell research, permits the destruction of human embryos.

This debate was transposed to the PCBE's discussions on the status of the human embryo, and in the report *Human Cloning and Human Dignity* the committee presents three different positions. The majority view holds that the human embryo is human and

therefore “one of us”. The other minority views claim that, firstly, the “human embryos develop intermediate moral growth that the human embryo has a moral status somewhere between that of ordinary human cells and that of a full human person,” and secondly, the use and destruction of human embryos presents no moral problems because embryos do not have moral status.⁵⁵

Having said this, the first major task bestowed upon the PCBE was to examine the ethical, legal and social issues associated with stem cell research and related technologies. To gather information on how the public views stem cell research, individuals came before the committee to talk about their perspective on the stem cell issue and the status of the human embryo. The transcripts from meetings reveal that a majority of the individuals who did speak before the committee represented religious associations, bioethics and professional associations, and patient advocacy groups. Scientific organisations were not represented and less than a handful of ordinary citizens made the trip to discuss the issues with the committee. The lack of representation from these latter groups is due to the fact that the committee does not “go out” to get public views. It waits for the people to come to them.

This approach can be problematic for several reasons. Firstly, individuals that are unable to attend cannot share their views. Therefore, this method of including the public restricts and limits opinions to those organisations that have the means to send representatives on the particular selective days during which the committee members are meeting. Secondly, what views are garnered during these sessions is reflective of a skewed perspective on stem cell research. In this case, there was a lack of lay persons and scientific representatives which many claim has contributed to the final outcome in first

report *Human Cloning and Human Dignity* (2002), then in *Monitoring Stem Cell Research* (2004), and finally in *Alternative Sources of Human Pluripotent Stem Cells* (2005).

Like Americans, Canadians questioned the moral status of the human embryo. Religions and advocacy groups held positions that reflect those values supported by their American counterparts. The policy void however created uncertainty around the use of human embryos for research. In response to a growing number of inquiries an ad hoc working group was formed by the Canadian Institutes of Health Research (CIHR) to address the issues.⁵⁶ The group's purpose was to temporary fill a regulatory vacuum by developing guidelines relative to stem cell research. While the working group developed a statement on stem cell research, CBAC was involved in the identification of the various issues that needed clarification such as the commercialization of embryos, however, the committee was working in collaboration with the CIHR as many of the experts participated in both committees simultaneously. The second round of discussions on the CIHR policy statement mainly involved stakeholders leaving little room for discussion with the general public.

Eventually, the CIHR together with the Natural Science and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC), the CIHR developed an important policy statement titled *Tri Council Policy Statement: Ethical Conduct for Research Involving Humans* (1998) which provides guidance as to what types of experiments involving human pluripotent stem cells should be funded.⁵⁷ As concerning embryonic stem cell research these guidelines are very thin, and for this reason the CIHR has adopted additional guidelines, which permits the

harvesting of stem cells from “spare” embryos created by in vitro fertilization, and given the sketchy ethical framework in this area, the CIHR has created a National Stem Cell Oversight Committee to provide ethical review of all CIHR-funded research involving human stem cells.⁵⁸

In addition to this policy, the Government of Canada in May of 2001 drafted legislation on *Assisted Human Reproduction* in response to a memorandum made by CBAC. At the same time, the Parliamentary Standing Committee on Health presented its research in support of the draft legislation as regards to the use of embryos for stem cell research. It was not until March of 2004 that the *Assisted Human Reproduction Act* successfully passed through the House of Commons and the Senate. In large part, the Act prohibits a number of activities, including: reproductive and therapeutic cloning, the creation of embryos for research purposes, germ line alterations, non-medical sex selection and commercial surrogacy.⁵⁹ However, the general premise is to protect the health, safety and human dignity of all Canadians. Until now, the Canadian view, in general, is to control the private sector whose main preoccupation is to conduct research on human embryos and the derivation of stem cells with *the Assisted Human Reproduction Act*, while at the same time guiding publicly funded research on embryos with the guidelines of both the Tri-Council and the CIHR.

1.6 Research Methodology

The case studies examined in this thesis were selected on the basis of showing how two groups, composed of many qualified and prestigious professionals, can fail at fostering public deliberation. I have chosen to focus my examination of public

deliberation and national bioethics committees on North America because it provides two distinct governance systems: a presidential system and a parliamentary system. Each have their own procedures and institutional legacies that have an impact on how modern day bioethics committees function.

The collection of data for the two case studies was obtained via literary sources such as journals, periodicals, manuscripts, as well as government documents. However, the analysis presented in the fourth chapter primarily draws upon committee and public hearings transcripts and reports from both the PCBE and CBAC, and peer interviews given by the chairs and members of both committees. This type of documentation provides excellent insight into how the committees function, how they interact with the general public, and their discussions on the stem cell issue.

Members from both committees have also done extensive work in the field of stem cell research, and I have been able to collect and analyse many peer reviewed manuscripts, correspondence and commentary pieces which allows for some insight into their personal opinions on the destruction of human embryos for research purposes that may or may not have been expressed during committee meetings. I also scanned policy statements and press releases from a variety of religious organisations, patient advocacy groups, scientific and medical associations, and bioethics organisations to review the state of the debate when both the PCBE and CBAC were studying the issue. This type of search provided information on the ethical, moral, legal, and social debate, which are juxtaposed with committee discussions.

The information I gathered from the literature aided in contextualizing the stem cell debate, and where the PCBE and CBAC fit into that debate. In addition to this scan, I

had the privilege of working with the Italian National Bioethics Committee in May of 2005. During my stay in Rome, I collected information on the stem cell issue and observed how the Committee worked and engaged with the Italian public. From my discussions with Mrs Cinzia Caporale, member of the National Bioethics Committee and Chair of the Intergovernmental Bioethics Committee of UNESCO, I was able to complete my understanding on how they work to inform the public. Also, I took advantage of my stay in Rome to interview Dr. Francesco d'Agostino, who is the current president of the bioethics committee.

What I learned in Rome added to my knowledge of public deliberation and stem cell research. I have since been able to discuss this topic with other scholars who work in the area of ELSI (ethical, legal, and social issues) pertaining to genetics and genomics. I had the privilege to talk to five scholars and professors on the issue, many of which are stationed at the University of Montreal in various departments, and others from international institutes such as the Chicago Kent University. These consultations were casual and unstructured and were juxtaposed with my general research to corroborate the findings.

1.7 Overview of the Chapters

Chapter two presents a literature review on what constitutes an ideal public deliberation model. It examines the dynamics of the experts who are dedicated to researching and providing technical advice, and their role in science policymaking. It also discusses the challenges to creating public forums and to manage issues of national concern. The incorporation of citizens in science policymaking is key to this discussion,

and drawing from the literature on deliberative theory, I explore how to incorporate an ideal deliberative model in the science and technology policymaking arena.

Chapter three discusses national bioethics committees as mechanisms of public deliberation. It is argued by some scholars that bioethics committees have the power and information to educate and persuade the public. In this chapter, I explore this claim and delineate what is an ideal mechanism of public deliberation. I also operationalize its functions to successfully foster public deliberation and how they could be instrumental at creating public debates.

Chapter four contextualizes the stem cell research debate by looking at the different arguments and worldviews held among stakeholders. It is believed that there are strictly two ways to view the stem cell debate- for or against stem cell research. This chapter shows that this belief is false, and that the stem cell issue is multifaceted, making it difficult for citizens, stakeholders and policy makers to agree upon a single solution. To determine how the American and Canadian publics responded to this debate, this chapter looks at the different viewpoints and traces them to the meetings held by both the PCBE and CBAC. The chapter also explores the history of stem cell policy in the U.S. and in Canada.

Chapter five offers an analysis of the two case studies. It shows that both committees were introduced to the stem cell issue for different reasons, and approached the concept of public deliberation from alternate starting points. For example, to reach its recommendation, the PCBE consulted various opinions from different stakeholders. However, public forums were limited to committee meetings. While this public engagement strategy fulfilled the requirements of the Federal Advisory Committee Act

(FACA)⁶⁰, it fell short when weighed against the ideal model provided by deliberative theorists. This shows that the relationship between national bioethics committees and public deliberation on the stem cell question is 'thin'. To complete the analysis of the case studies, this chapter presents a comparison between the PCBE and CBAC and how both committees failed to foster a national discourse on the stem cell research.

In conclusion, the last chapter presents an overview of the findings. It discusses the challenges involved when including non-experts in science policy making and how deliberative theory presents the ideal model for 'bringing' the public back into the policy realm. More importantly, this chapter discusses what this study has purposely not addressed and what the findings suggest for the future of public deliberation in science policy making.

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- ¹ Ira Carmen, *Politics in the Laboratory: The Constitution of Human Genomics* (Madison Wisconsin: The University of Wisconsin Press, 2004) 341.
- ² Ibid.
- ³ Cynthia B Cohen, "Stem Cell Research in the U.S. After the President's Speech of August 2001," *Kennedy Institute of Ethics Journal* 14 (1) (2004): 97-114.
- ⁴ President's Council on Bioethics (PCBE), *Monitoring Stem Cell Research*, Washington DC 2004, 9.
- ⁵ An egg cell from which the nucleus has been removed.
- ⁶ Cohen CB (2004), 99.
- ⁷ The President's Council on Bioethics (PCBE), *Alternative Sources of Human Pluripotent Stem Cells*, Washington DC 2005, 1-99.
- ⁸ Ibid.
- ⁹ Ibid.
- ¹⁰ Jane Maienschein, "Part II- What's in a Name: Embryos, Clones, and Stem Cells," *American Journal of Bioethics* 2(1) (2002): 19.
- ¹¹ Laurie Zoloth, "Part 1: Jordan's Banks, A View from the First Years of Human Embryonic Stem Cell Research," *The American Journal of Bioethics* 2(1) (2002): 3.
- ¹² It is important to note that recent literature on the subject uses the terms advisory committee, advisory commissions, and bioethics committee interchangeably. This thesis will use the term bioethics committee to mean the same as advisory body and committee throughout this analysis.
- ¹³ Mary Richardson, et al., *Winning Back the Words: Confronting Experts in an Environmental Public Hearing*, Toronto: Garamond Press, 2003; Frank Fischer, "Technological Deliberation in a Democratic Society: The Case for Participatory Inquiry," *Science and Public Policy* 26(5) (1999): 295.
- ¹⁴ Madison Powers, "Bioethics as Politics: The Limits of Moral Expertise," *Kennedy Institute of Ethics Journal* 15(3) (2005): 305.
- ¹⁵ Lawrence Pratchett "New Fashions in Public Participation: Towards Greater Democracy?" *Parliamentary Affairs* 52(4) (1999): 619.
- ¹⁶ Morris Shamos, *The Myth of Scientific Literacy*, New Brunswick, NJ: Rutgers University Press, 1995; Ibid.
- ¹⁷ John Durant, "Participatory Technology Assessment and the Democratic Model of the Public Understanding of Science," *Science and Public Policy* 26(5) (1999): 314.
- ¹⁸ Jon D. Miller, "Public Understanding of, and Attitudes Toward, Scientific Research: What We Know and What We Need to Know," *Public Understand. Sci.* 13 (3) (2004): 273; Sally Macintyre, "The Public Understanding of Science or the Scientific Understanding of the Public? A Review of the Social Context of the 'New Genetics,'" *Public Understanding of Science* 4 (1995): 223-232.
- ¹⁹ Ibid.
- ²⁰ Benjamin R. Bates, "Public Culture and Public Understanding of Genetics: A Focus Study Group," *Public Understanding of Science* 14 (1) (2005): 52; Ian Barns, Schibeci R, Davison A, and R Shaw, "What do you think about Genetic Medicine? Facilitating Sociable Public Discourse on Developments in New Genetics," *Science, Technology, & Human Values* 25(3) (2000): 283-308.
- ²¹ John Durant (1999), 315.
- ²² Peter deLeon, "Models of Policy Discourse: Insights versus Prediction," *Policy Studies Journal* 25(1) (1998): 148.
- ²³ Frank Fischer, "Beyond Empiricism: Policy Inquiry in Postpositivist Perspective," *Policy Studies Journal* 26(1) (1998): 4.
- ²⁴ Ibid., 6.
- ²⁵ Frank Fischer, *Evaluating Public Policy*, Chicago, IL: Nelson-Hall, 1995, 243.
- ²⁶ Frank Fischer (1998), 15.
- ²⁷ Harold D. Lasswell, "The Policy Orientation," in D Lerner and HD Lasswell (eds.) *The Policy Sciences* Stanford, CA: Stanford University Press, 1951, 3-15.
- ²⁸ Udaya Wagle, "The Policy Science of Democracy: The Issues of Methodology and Citizen Participation," *Policy Sciences* 33 (2000): 210.
- ²⁹ Christian F Rostboll, "On Deliberative Democracy," *Nordic Journal of Philosophy* 2(2) (2001): 166.
- ³⁰ Information on this 'enlightening' experience via public deliberation can be found in the work of Robert Dahl.
- ³¹ Marion Young, *Inclusion and Democracy* Oxford: Oxford University Press, 2000, 26.

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- ³² Maeve Cooke, "Five Arguments for Deliberative Democracy," *Political Studies* 48 (2000): 948.
- ³³ *Ibid.*, 949.
- ³⁴ Amy Gutmann, and Dennis Thompson, *Democracy and Disagreement*, Cambridge: The Belknap Press of Harvard University, 1996, 53.
- ³⁵ Joshua Cohen, "Deliberation and Democratic Legitimacy," in *Essays on Reason and Politics: Deliberative Democracy* (eds) James Bohman and William Rehg, Cambridge: The MIT Press, 1997, 72.
- ³⁶ Joshua Cohen, "Pluralism and Proceduralism," *Chicago Kent Law Review* 69(3) (1994): 610.
- ³⁷ Peter deLeon (1998), 152.
- ³⁸ Lawrence Pratchett, "New Fashions in Public Participation: Towards Greater Democracy?" *Parliamentary Affairs* 52(4) (1999): 628.
- ³⁹ John Durant (1999), 315.
- ⁴⁰ Thomas Christiano, "The Significance of Public Deliberation" in *Essays on Reason and Politics: Deliberative Democracy* (eds) James Bohman and William Rehg London: MIT Press, 1997, 243.
- ⁴¹ Thomas R Wolamin, *Presidential Advisory Commissions: Truman to Nixon* Madison, Wisconsin: The University of Wisconsin Press, 1975, 28.
- ⁴² *Ibid.*, 30.
- ⁴³ Alan L. Dean, "Ad Hoc Commissions for Policy Formulation" in TE Cronin and SD Greenberg (eds.) *The Presidential Advisory System* New York: Harper and Row Publishers, 1969, 104-106.
- ⁴⁴ *Ibid.*, 15.
- ⁴⁵ HDGraham, "The Ambiguous Legacy of Presidential Commissions" *Public Historian* 7 (2) (1985): 5-25.
- ⁴⁶ Amy B Zegart, "Blue Ribbons, Black Boxes: Toward a Better Understanding of Presidential Commissions," *Presidential Studies Quarterly* 34 (2004): 366-93.
- ⁴⁷ Thomas R Wolamin (1975), 146-151.
- ⁴⁸ Felix Frankfurter was a professor at Harvard Law who specialized in labor law. He also served as an informal advisor to President Roosevelt who also nominated Frankfurter as Supreme Court Justice.
- ⁴⁹ Thomas R. Wolamin (1975), 35.
- ⁵⁰ Mary B. Mahowald "The President's Council on Bioethics, 2002-2004," *Perspectives in Biology and Medicine* 48(2) (2005): 160.
- ⁵¹ *Ibid.*
- ⁵² *Ibid.*
- ⁵³ *Ibid.*
- ⁵⁴ Lisa H. Harris, "Ethics and Politics of Embryo and Stem Cell Research: Reinscribing the Abortion Debate," *Jacobs Institute of Women's Health* 10(3) (2000): 147.
- ⁵⁵ President's Council on Bioethics (PCBE), *Human Cloning and Human Dignity: The Report of the President's Council on Bioethics*, New York: Public Affairs, 2002, 153.
- ⁵⁶ Canadian Institutes of Health Research (CIHR), *Human Stem Cell Research: Opportunities for Health and Ethical Perspectives*, Ottawa 1998 available at <http://www.cihr-irsc.gc.ca/cgi-bin/print-imprimer.pl>.
- ⁵⁷ *Ibid.*
- ⁵⁸ Francoise Baylis, "Human Embryonic Stem Cell Lines" The Ethics of Derivation," *J Obstet Gynecol Can* 24(2) (2002): 160; J Hoey, "The Environments of Stem Cells-Biology, Ethics and Policy," *CMAJ* 166(8) (2002): 1005; Canadian Institutes of Health Research (CIHR), *Updated Guidelines for Human Pluripotent Stem Cell Research*, 2005 available at: <http://www.cihr-irsc.gc.ca/e/28216.html>.
- ⁵⁹ Timothy Caulfield, "Bill C-13 The Assisted Human Reproduction Act: Examining the Arguments Against A Regulatory Approach," *Health Law Review* 11(1)(2002): 20.
- ⁶⁰ Requires commissions to have meetings in the open public, solicit public comments on committee publications, and place notices of meetings in the Federal Register. In the U.S., all advisory bodies are governed by the Federal Advisory Committee Act (FACA), which requires committees to release specific information to the public, and to conduct open meetings as well as solicit commentaries from the general public. This Act was created with the intent to promote transparency and accountability in the administration of advisory bodies.

Chapter 2

Public Deliberation and Policy-Making

2.1 Returning to Deliberative Politics

The first serious works in genetic research sparked a combination of public interest and fascination. Enthralment later gave way to fear prompted by the possibility that advances in genetic research may be used not only for purposes that everyone agrees are good, triggering initial caution and then legislation to limit this kind of research.^{1,2} At present, legal intervention addresses concerns about political and commercial interests in genetics and genomics and the misuse of public funds for such research. Moreover, the ability of governments to deal with the anxieties of stakeholders is uncertain; regulators approach their task with caution and under scrutiny.³ These worries have initiated strong public demand for more citizen involvement in the governing of genetic technologies.

However, there are many sceptics who question the ability of ordinary citizens to properly evaluate what is best for the broader society. When faced with complex ethical, social and scientific issues, identifying potential solutions can be difficult for it requires specialized knowledge and training. This critique of public deliberation originated from the UK in the early 1980s, where the term “public understanding of science” first emerged.⁴ From the outset, researchers subjected the phrase to public scrutiny with claims that citizens lack the understanding required to be able to follow and participate in public policy discussions of a scientific or technological nature.^{5,6} Furthermore, there are additional concerns that citizens are unable to appreciate current scientific as well as social theories, practices, and relationships and institutions- that is, the particular social contexts into which new science and technology including the new genetics and

genomics will be introduced.⁷ As a result, divisiveness over the role of the general public in scientific issues has raised considerable debate.

In fact, over the past 25 years, these concerns have slowly but gradually found expression in public protests in western societies, as citizens have increasingly challenged the arrogance and elitism of professional encroachments into public and private life.⁸ Some scholars claim that western societies in general feel “betrayed” by governments and experts. For example, Sale writes that public concerns are prevalent not only “on the dissenting edges of academic economics and ecology but everywhere”.⁹ Furthermore, the majority of current scientific research is dependent upon public funding. Growing public demand for greater accountability in the allocation of public monies in scientific research along with the social, moral, and legal implications of scientific and technological advancements requires that governments integrate public dialogue into science and technology policy-making.¹⁰ Including citizens in science policymaking is, however, not without challenges.

On the one hand, traditional tools of legislative avenues of decision making remain essential, but they have also at times become deadlocked or have alienated communities.¹¹ Public deliberation has emerged as a potentially valuable way of breaking (or at least sidestepping) this deadlock.¹² According to Chambers, “democratic deliberation begins with a turning away from liberal individualist or economic understandings of democracy and toward a view anchored in conceptions of accountability and discussion.”¹³ James Bohman expands this concept by stating that deliberative democracy is, “a process of forming a public reason—one that everyone in the deliberative process finds acceptable.”¹⁴ Finally, Christiano explains that discussion and

deliberation promote greater understanding of the interests of the members of society, as well as how the common features of the society relate to those interests.¹⁵

On the other hand, sceptics reject this approach and challenge it as being a utopian rhetoric of politics.¹⁶ Cynics claim to have identified fundamental problems regarding the inclusion of citizens in science policymaking. Firstly, public deliberation does not inspire individuals to share their reasoned views but provides the perfect scenario for collective action. For example, when people believe that their reasons have been taken into account and that they have been listened to, they can sometimes accept results that otherwise they would not.¹⁷ Also, there is the argument that people with extreme views tend to have more confidence that they are right, and that as people gain confidence they become more extreme in their beliefs.¹⁸ Extreme arguments also lead to group polarization that is often experienced in ethnic and religious feuds and strife. Other critics claim that deliberative models challenge the premises of traditional representative democracy.¹⁹

However, if we were to accept these perspectives, citizens would no longer meaningfully participate in public policy and they would be compelled at some point to accept a minimalist conception of democracy (that is being restricted to representative democracy).²⁰ For proponents of public deliberation, deliberation is a perfect method of including citizens in debates on issues of national concern. If conducted on a large scale, it can involve citizens from different demographic regions within a country allowing citizens with various interests to participate and express their concerns and share their values. These discussions feed into the policy process and enhance potential options for science policy formation. At the same time, public deliberation helps to raise awareness, educate, and stimulate discussion within smaller communities.

It is important to stop here for a moment to briefly discuss about what proponents of public deliberation mean when they talk about including the “public” in policy making. It is safe to say that a majority if not all deliberative scholars talk about a broad cross section of “lay individuals”.²¹ In other words, these “lay individuals” are associated with different groups within an ever evolving society such as families, communities, religious groups, work related groups and many others depending on social identities and personal lifestyles. They are not categorized as state actors because these groups are often called upon to represent the masses. Proponents of public deliberation encourage the engagement of actors that lie outside the political arena.

The literature uses several different terms to describe “citizens” and “public”. For example, the private activities of consumption of today’s global citizen has led to the use of the term “consumers” within the public deliberation literature because, these activities are regarded as having an impact on society.²² Nonetheless, there is widespread recognition that the terms “consumers”, “public”, “citizen”, “lay people”, “clients”, “patients”, “residents”, “survivors” or “recipients” are used in relation to the situations and experiences of the individuals being addressed.²³ From all of these standpoints, public deliberation is defined in terms of the struggles, lifestyles, morals and values of individuals.²⁴

Today, citizens are most likely brought to engage in deliberation through institutionally organised events at local and national levels. In fact, political scientists have recognized that the range of public participation techniques has grown significantly over the years. Political scientists Parry, Moyser and Day found in their 1992 study on public participation techniques that 18% of public bodies have used citizen juries, 47%

had commissioned focus groups and 45% had undertaken some form of community planning.²⁵ The current preoccupation with new modes of participation can be traced back to a variety of potential sources.²⁶ Some of these methods of public engagement have their roots in the citizen-consumer agenda of the 1980s, while others emulate private sector management techniques such as consumer trials and consultations.²⁷ However, these opportunities have varied in methods over time. Opponents of public deliberation claim that not all methods are successful and that specific criteria or characteristics are relevant to promoting ideal public deliberation. More particularly, sceptics such as Barabas, Page and Shapiro question how well deliberation actually works, what kind of mechanism is necessary and under what circumstances public deliberation succeeds.²⁸ This chapter is dedicated to operationalizing how ideal public deliberation works by drawing from deliberative theory, which has shown to be a good source for determining what ideal public deliberation is.

2.2 Ideal Public Deliberation

Deliberative theory first emerged as a counterargument to applying lessons and procedures of the natural sciences to social science settings.²⁹ As a post-positive movement, deliberative theory evolved into an ideal way of reintroducing citizens into the political arena without compromising existing political structures. The idea of public deliberation is not new.³⁰ Its origins can be traced to the public interest movements of the 1960s and 1970s when participatory processes were, for the most part, relegated to particular areas of society.³¹ Its real aim is to critically investigate the quality, substance

and rationality of arguments and reasons brought to express support or disdain for policy and law.³²

Over the years, deliberative theorists have divided themselves into two respective camps: proceduralists and non-proceduralists. Both hold to values and principles that govern public deliberation and that are intended to establish fair terms of political cooperation in a democratic society.³³ These principles include basic liberty, fairness to persons and mutual respect for different views and notions of reciprocity, publicity and accountability.³⁴ Some of these principles or values are more important than others depending on the theorist and their view of what ideal public deliberation should entail.

A good example is Gutmann and Thompson's view that reciprocity is a leading principle for deliberative theory. They deem this principle extremely important when dealing with moral and ethical disagreements. They claim that reciprocity is a concept that seeks fair terms of social cooperation for citizens aspiring for a kind of political reasoning that is mutually justifiable, and requires citizens to justify their moral positions on an issue via a "reason giving process".³⁵ For example, the two most vocal and opposing camps in the stem cell research debate have been the pro- research supporters and the pro-life proponents. The latter argue that embryos are humans and they should not be created and destroyed for the purpose of research. The former argue that research in this area should move ahead given the enormous potential of stem cells to cure numerous diseases. These opposing views stem from many common moral and ethical beliefs held by citizens, and while not all citizens express their views or concerns, they nonetheless have opinions about stem cell research.

In cases where interlocutors hold strong religious views and are deemed as “fundamentalists” or “extremists”, Gutmann and Thompson argue that they should be excluded from deliberation as these views halt the deliberation process. This phenomenon is also known as group polarization. In brief, it means that the members of a deliberating group predictably move toward a more extreme point in the direction of their pre-deliberation views.³⁶ For example, when an interlocutor discusses ethical issues relating to research on embryos with a person who believes in the sanctity of life, things get problematic because, a religious individual’s ‘world taken for granted’ must be legitimated over and over again, against competing views held by other religions, as well as other institutions of modern society, such as science.^{37,38} Depending on how debates on embryonic research proceed, either pro-life proponents or pro-science proponents will view that their positions are not being respected.

While reciprocity does not always produce agreement, it encourages citizens to discover what aspects of their beliefs could be accepted as principles and policies by other citizens with whom they fundamentally disagree.³⁹ Tolerance and mutual respect must be nurtured through conversation, not mere debate but the disciplined act of communicating and listening.⁴⁰ Interestingly, the principle of reciprocity itself is neither a purely procedural nor substantive principle.⁴¹ Usually, a reciprocal perspective is both procedural and substantive because mutual justification, according to Gutmann and Thompson, cannot proceed without appealing to reasons that refer to both procedures of government and substance of laws, often at the same time.⁴² Gutmann and Thompson also stress the importance of publicity, which is generally described as open justification

of actions by officials and citizens demonstrating accountability. These principles, according to Gutmann and Thompson, are fundamental to public deliberation.

Other deliberative theorists such as Joshua Cohen and Seyla Benhabib, often considered strict proceduralists, claim that procedures are tantamount to all other aspects of public deliberation because they set the boundaries of deliberation and ensure that deliberation outcomes are just and fair. The premise of this objective is to guarantee that deliberation is fair and that the outcome of the deliberative process is equally fair making the process of public deliberation the source of legitimization.⁴³ It has, however, been argued by non-proceduralists that public deliberation procedures can be manipulated to marginalize certain groups. Proceduralists respond to this critique by arguing that participants predetermine the processes of public deliberation making it difficult for anyone to manipulate the outcome.

Non-proceduralists also claim that there is the aspect of substance, which is equally important to public deliberation. Substance can be generally defined as the qualities of human experiences and social relations. What has created much trouble for deliberative theorists is identifying the difference between the reinforcement of substantive concepts that exist in a democratic society such as justice, equality, freedom of expression, and liberty and the official rules of democracy.⁴⁴ This has led to an important debate among deliberative theorists. In fact, much ink has been spilled in the literature about what is more important in public deliberation - procedure or substance? What has been central to this debate is whether there are any limits to the content of what can be decided democratically.⁴⁵ Many substantive issues touch upon basic human rights

and liberties that are also part of what many citizens consider normative positions, morals, and values.

Within the community of deliberation advocates, there exists many disagreements over techniques and priorities, but there appears to be an unrecognized overlapping consensus on the criteria for high quality deliberation (see table in appendix).⁴⁶ Most agree that public deliberation has the following features: a) a realistic expectation of influence (i.e. link to decision makers); b) an inclusive, representative process that brings key stakeholders and publics together; and c) an informed, substantive, and conscientious discussion, with an eye toward finding common ground.⁴⁷ Both camps also agree that public deliberation is participant focused. In other words, citizens are encouraged to consolidate and develop co-membership in a collective form of life by way of public reasoning with other citizens who owe their identities to the same values and traditions.⁴⁸

To accomplish this, however, there must be a focus on citizen education and raising awareness. Good deliberation must begin with educating citizens and stakeholders alike on the issues of concern. This gives citizens an opportunity to identify shared ideas through reciprocity and assign priority to issues of national concern.⁴⁹ A public agency is usually then put into place to set the rules that regulate where, when, and how deliberators can engage in dialogue. Discursive participation can include but is not limited to the formal institutions and processes of civic and political life.⁵⁰ It can involve private citizens in informal, unplanned exchanges.⁵¹ Today, however, governmental institutions such as agencies or advisory bodies are often given the task of organizing public deliberation activities.

These institutions ensure that all policymakers, experts, citizens and stakeholders have equal access to discussions. This emphasis on ‘all citizens’ has much to do with what Joshua Cohen calls a ‘principle of deliberative inclusion’, which goes beyond the simple exchange of information or the gauging of public opinion.⁵² It involves knowledge processing between deliberators. An example of such an effort would involve ongoing deliberation between policy makers, experts, citizens and stakeholders that begins at the agenda setting stage of the policy making process and ends with the monitoring stage. In other words, a well-defined process that employs the development of effective policymaking through public deliberation involves: a) defining of a problem of national concern; b) educating the public about the issue; c) identifying the criteria to be used in the evaluation of alternative solutions; d) assess public opinion about a set of options; e) persuade the public of a suitable course of action via a recommendation; f) comply with the public on legal norms and requirements; and g) follow-up on the issue through oversight and evaluation.⁵³

Authentic public deliberation is therefore a deep and continuous involvement in the policymaking process with the potential for all involved to have an effect on the situation.⁵⁴ The continuous aspect of public deliberation is imperative for its success as it legitimizes discussions and generates acceptance for all those involved. However, current participatory methods do not keep deliberation continuous.⁵⁵ Ambivalence toward the necessity of public deliberation has left many citizens and stakeholders out of the policymaking process and away from the framing of issues. For example, one-shot public hearings often provide citizens with little opportunity to engage in dialogue with policymakers because, such meetings lack follow-up sessions, making it difficult for

citizens to view the policymaking process as responsive to their moral, ethical, or existential concerns.⁵⁶

An ideal technique for fostering public deliberation includes a consensus conference. Consensus conferences can be characterized as public meetings with experts and citizens. The original consensus conference originated in the United States, where they were used by the National Institutes of Health to bring medical experts together to assess the safety and efficacy of medical technologies.⁵⁷ These meetings were adapted to European needs during the 1990s and have become a signature component of citizen engagement strategies for countries like The Netherlands and Denmark. Consensus conferences have also been most frequently applied to problems of science and technology, where this form of democratic citizen participation helps to clarify issues, questions, and concerns of the general public.⁵⁸

In its essence, the consensus conference rests upon the interaction and deliberation between citizens and experts based on a set of key questions developed by a citizen panel.⁵⁹ These key questions set the stage for deliberation and debate, which is characteristically advocated by deliberative theorists such as Cohen and Bohman, who place significant emphasis on this kind of interaction. The advantages of a consensus conference are that it has the potential to tap into communal identities and views. Its outcomes are also the product of processes that are based on communication between individuals.

Other ideal ways to foster public deliberation is through national issue forums, and citizen juries. These techniques focus on encouraging participants to work towards discussing issues of concern in order to develop policy options.⁶⁰ Even if these

deliberation techniques vary slightly in their methods, there is nonetheless a high degree of similarity among them.⁶¹ All of these techniques are inclusive and elicit dialogue, opinions, and feedback.

It is clear from this discussion that the operational requirements of public deliberation are daunting.⁶² Authentic or ideal public deliberation is an iterative process with multiple exchanges as the dialogue proceeds.⁶³ It places citizens next to the issue and has a direct impact on the processes and outcomes.⁶⁴ This makes the overall benefit of public deliberation the reduction of conflict between policy interests but also open-ended public dialogue, which shows that when people engage in a conversation neither side loses and both are changed, because they now know what reality really looks like from a different perspective.^{65,66}

2.3 Ideal Public Deliberation for Science Policy

Public policy research is a major subfield in political science to embrace deliberative theory.⁶⁷ The trend toward accepting a more social view of public policy began with Harold D. Lasswell and his concept of the ‘policy sciences of democracy’. His concern was that policy scientists were acting more like experts rather than policy analysts. From this concern, Laswell’s idea of strengthening democracy and its values through participatory processes emerged. Most have considered this idea the principal factor for the early definition and subsequent articulation of the policy sciences of democracy, which moved away from the strong empirically driven research methods dominating the field of policy studies also known as the positivists approach.⁶⁸ Douglas Torgerson captures the essence of the positivist perspective in the following text⁶⁹:

The positivist spirit would rigorously distance itself from the speculations of theology and metaphysics, confronting the world objectively in order to observe the facts that determine the lawful order of nature and society. The domain of mystery and ambiguity would be abandoned in order to know what could be known clearly and certainly.⁷⁰

Today, science policy is one area still considerably dominated by this view. In other words, there is still a strong demand for scientific evidence to inform science policy, which in turn has created a strong need for policy experts. In the earlier part of the genetics revolution, policy experts played an uncontested role in the development and implementation of science policy. Historically, science and technology research has been under the auspices of government control and used for defence and warfare purposes, but gradually government control over research waned as research programs began to be transferred to more adept facilities such as universities, research centres of excellence and the private sector. This shift resulted in a special relationship between government, universities and private industries, but it also led to supremacy of privately funded R&D.⁷¹

The transformation in funding has also significantly changed R&D methodology, particularly, the way researchers move across institutions and disciplines.⁷² For example, SUN Microsystems, now one of the world's leading developers of computer networking was originally developed at Stanford University, and at the same time, Novartis, a Swiss pharmaceutical giant, funds the University of Berkeley to conduct basic research in the Department of Plant and Microbiology.⁷³ This new relationship between government, universities and industry raises serious questions concerning research ethics, but also about the role of the researcher or expert, and the role of universities and the private sector in science and technology.⁷⁴

Today, many rising researchers and experts have had the opportunity to be trained by high quality research groups and centres that are funded by private sector companies. As public funding for certain research topics have diminished, researchers have turned towards the private sector for funds as mentioned above with the example of SUN Microsystems and Novartis. It is not uncommon for these research projects to have an educational component, that is, training graduate students as researchers. This expansion of educational opportunities has had a major impact in moving educated individuals outside the research environment and out of traditional research institutions and into privately funded institutions.⁷⁵ Many of these highly educated individuals have moved beyond the “ivory tower” and have become expert advisors for decision makers and the private sector. Most are highly skilled individuals and have the ability to develop, create and understand knowledge within the scientific and technological fields.⁷⁶ Eventually, these students go on to work for the governments as policy experts where they have for practically two decades monopolized the science policymaking arena.

According to Schneider and Ingram, this is due to experts’ control of information and the institutions that are used in policymaking. Experts hold homogenous scientific knowledge gained through technical methods for policy analysis.⁷⁷ Accordingly, scientific knowledge is normatively constructed in such a way in which policy experts believe policy problems can be understood. That is through the application of scientific theories and empirical methods of exploration and not through the involvement of non-experts.⁷⁸

The challenge put forth by many deliberative theorists such as Fischer is to situate empirical policy research in a larger set of normative concerns that give its findings

meaning.⁷⁹ In other words, basing policy analysis on subjective understandings of value systems that are important in societies.⁸⁰ The need for this kind of analysis emerged from what many postpositivists argue is the failure of most public policies to incorporate social norms and values.⁸¹ Scientific knowledge has also been ineffective at providing solutions to the social and moral concerns raised by science and technology.⁸²

Until fairly recently, the public's role in science policy has been limited. Namely, the public has responded to specific topics on policymakers' minds only when asked, leaving very little time for individuals to reflect and think about the issues.⁸³ Frank Fischer, for one, has advocated for a more participatory process in science policymaking. He argues that conventional models that predominantly involve experts and scientific expertise are insufficient and unsatisfactory. According to Fischer, "Far too little systematic attention has been devoted to the ability of citizens to participate meaningfully in an age dominated by complex technologies and expert decisions."⁸⁴

Another public deliberation supporter, Sheila Jasanoff, has argued that the evolution of science is moving at a rapid pace, far faster than anyone has ever imagined and with it are citizen movements that have become deeply involved in science policy as they seek a more 'open government' approach to policymaking.⁸⁵ This, along with the decline of public trust in governments has contributed to the movement seeking a more deliberative society. A similar position is advocated in the study performed by Bruce Ackerman and James Fishkin in *Deliberation Day*. In this particular study, Ackerman and Fishkin show that the 'veil of ignorance' must be confronted, especially in the area of science and technology, and that we must envisage real people under realistic conditions making actual policy choices.⁸⁶

Public deliberation is a perfect way to assist citizens in their efforts to examine their own interests and to make their own decisions about science.⁸⁷ Fischer argues that collaboration through participatory techniques such as consensus conferences can yield better policy solutions, while at the same time empower citizens with increased access and information to bring valuable inputs, propose various alternatives, and substantiate local knowledge.⁸⁸ The relationship between policy experts and citizens, Fischer maintains, involves mutual determination of goals, a shared spirit of inquiry, and equity among all.⁸⁹ It is often the case that people do not have well-informed values and opinions on relatively new topics, particularly in science and technology, until there is a public discussion or debate.⁹⁰ Authentic public deliberation provides a process to organize public deliberation and for citizens to have a proactive role in science policy.

2.4 Conclusion

Only lately has a need for public deliberation in a burgeoning scientific and technological society been recognized. Perhaps this need for public dialogue is greater now than before given the rapid advances in genetic and genomic research. The emergence of the scientific citizen has only propelled new public deliberation activities. However, many of these public deliberation efforts are insufficient in their methods and in their outcomes for the following reasons. Firstly, they are not participant-oriented. Secondly, they do not educate or inform citizens on the issues being addressed. Thirdly, access to public deliberation is restricted to a narrow range of stakeholders, and lastly, deliberation is not ongoing and open-ended, but one-way and usually performed in a top-down manner.

Ideal public deliberation entails a reason-giving process among stakeholders who respect each other and share in mutual reciprocal dialogue. This dialogue is continuous and open to all with the overall aim of achieving synergy in values and determining what is best for society as a whole. The intent is not to achieve consensus but to create a forum where citizens and stakeholder as well as policymakers and experts can debate issues of national concern. The criteria highlighted in this chapter necessary for authentic public deliberation are: a) oriented toward participants; b) open-ended discussions available to all; c) free flow of information between participants; and d) reciprocal respect among individuals.

Obstacles that can hinder the success of public deliberation include the practical realities of daily life. These tie in with issues of social class and include factors like time constraints, family structure, employment and economic disadvantages. There are also administrative processes that create barriers for public deliberation. For example, some public administrators or managers might view public deliberation as desirable while some may view public deliberation as a challenge to existing governmental structures. Those who view public deliberation as a challenge may wish to block progress in this area via the adoption of unreasonable administrative processes.

One way to overcome these obstacles is to empower citizens through education and designing public deliberation activities where citizens can freely access information about the potential impact they can have on science policy in particular. Ultimately, policy experts and policy theorists will take more seriously the question of how positive experiences in specific deliberative situations can translate into broader feelings of political competence.⁹¹ Given that this chapter has formally discussed what ideal public

deliberation is, the next chapter focuses on delineating an ideal mechanism for public deliberation and discusses the ideal circumstances that facilitate public dialogue on science and technology but more particularly stem cell research research.

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- ⁴ John Durant, "Participatory Technology Assessment and the Democratic Model of the Public Understanding of Science," *Science and Public Policy* 26(5)(1999): 313.
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- ⁶ Jon D. Miller, "Public Understanding of, and Attitudes Toward, Scientific Research: What We Know and What We Need to Know," *Public Understanding of Science* 13 (2004): 274.
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- ⁸ Mary Richardson, et al., *Winning Back the Words: Confronting Experts in an Environmental Public Hearing*, (Toronto: Garamond Press), 1993; Frank Fischer, "Technological Deliberation in a Democratic Society: The Case for Participatory Inquiry," *Science and Public Policy* 26(5) (1999): 295.
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- ²² W. Lance Bennett, "Introduction: Communication and Civic Engagement in Comparative Perspective," *Political Communication* 17(2000): 308.
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Chapter 3

National Bioethics Committees

3.1 Public Bioethics for Science Policy

Modern science and technology is moving at an alarming rate and the complexity of some fields constantly raise new challenges that policymakers need to address. National bioethics committees have emerged as ideal government institutions to investigate and address science and technology related issues. More recent role has them engaging in the science policymaking process by providing much needed input via recommendations to government. While the results of scientific progress may be new, national bioethics committees are not. The use of a bioethics committee can be traced to the 1990s, while the employment of a national advisory committee goes as far back as the presidency of George Washington.

What makes national bioethics committees ideal for addressing science policy issues is their expertise and ability to tap into important academic resources. Today, national bioethics committees are commonly composed of experts who have been trained by recognized government and academic institutions covering a range of fields including law, ethics, bioethics, medicine, political science, philosophy, sociology, anthropology, biology and sometimes other fields like microbiology and genetics. When appointed to a position with a national bioethics committee, these experts form a corporate group created by the government executive in a majority of cases mandated with ensuring transparency and accountability for government action or inaction. Members are usually drawn from outside government circles to ensure independence and non-partisanship but this is not always the case.

Interestingly, the study of national bioethics committees has not eluded scholars. Several scholars such as Wolanin and Flitner have endured the task of examining the characteristics and functions of national bioethics committees. Presidential historians and political scientists in particular have studied the role of advisory bodies in the executive branch.¹ Wolanin however provided the most original and groundbreaking work on national advisory committee. In his research, Wolanin found that there are four types of commissions: 1) crisis commission - a commission established in reaction to a crisis; 2) policy analysis commission - a commission that examines and proposes policy options to government; 3) issue management and avoidance commission – a commission established to bring attention to other issues; and 4) window dressing commission – a commission that brings credibility to policy choices and restores public integrity in governmental institutions.² Contributing to this endeavour, Graham identifies five different types: 1) reorganisational; 2) national goal; 3) crisis induced; 4) technical; and 5) major policy. Finally, Flitner's work in this area has contributed a typology of three broad categories: 1) procedure-oriented commissions; 2) situation-oriented commissions; and 3) crisis-oriented commissions.³

Zegart expands on these typologies to include three variant types of based on the tasks they are expected to perform. The first is the reactive agenda committee, which draws attention to and support for new policy initiatives.⁴ Then there are information committees that target a much narrower audience with the goal of improving policymaking by drawing widespread attention to or support for an issue or by removing an issue from the public agenda.⁵ Lastly, Zegart talks about a political constellation

committee, which aims to foster consensus, compromise and cooperation in the policy domain.⁶

These typologies are useful because they broadly group commissions according to the nature of the problem they address. In reality, however, we know that commissions come in an endless array of types that often include task forces, committees, groups and panels just to name a few.⁷ It is also known that commissions or committees for that matter do not squarely fit into any of these categories.

Each type of committee has a specific goal to achieve which distinguishes one type of committee from another.⁸ Committees also differ in terms of their life span and status. Ad hoc committees are deemed more effective than committees with permanent status because their work must be completed within a specific deadline. Moreover, the commonality of ad hoc committees has been growing exponentially as their effectiveness makes them more appealing to policymakers. They also add to public credibility. For example, the PCBE is an ad hoc committee that was created by a presidential executive order during a tumultuous public debate on stem cell research. The main purpose of the PCBE was to address all matters relating to biomedicine, in particular stem cell research, and to report its findings to the president. However, at the time of its establishment the president had already chosen his position on stem cell research, and it was argued by journalists that the PCBE was more of a window dressing committee than a policy initiative committee.

These characteristics make national bioethics committees appealing for governments seeking to invest in science policy research. Rapid progress in the development of human genetic technologies raises complex ethical, legal, social and

economic issues, which are constantly brought to the attention of citizens. Some scholars argue that governments seek to alleviate public concerns about genetic technologies by turning to national bioethics committees and using them as mechanisms of public deliberation. For example, Dzur and Levin argue that national bioethics committees are ideal institutions to foster public deliberation due to their characteristics and responsibilities.⁹ If Dzur and Levin are right, then we can only speculate that national bioethics committees have been used as mechanisms of public deliberation in order for governments to receive high level support for their science policy choices. Accordingly, it is also possible that governments have used national bioethics committees to produce recommendations based on information that clearly highlights the public's shared priorities.

However, there are some scholars that have raised doubts as to whether national bioethics committees have played any real role in science and technology policy. Some scholars see the role of bioethics committees as performing a latent function of validating and legitimizing action and the authority of science and policy actors.¹⁰ Many scholars worry that even when inviting stakeholders and the lay public to participate in discussion, their concerns and opinion are rarely included in their assessments and recommendations to government. Other scholars claim that policy makers often ignore recommendations made by bioethics committees, as there are other contingent and probably more political or ideological influences to consider.¹¹ Other scholars claim that public deliberation efforts by bioethics committees are in vain, because lay citizens are not adept enough to be involved in extremely technical debates. Arguably, this is primarily because the communication of risk is not a priority for the research community, leaving the public to

receive information about science and technology from the popular media. At the same time, there is the potential of conflict of interest among members selected to participate on these committees as they continue to hold close ties with the scientific community.

These counterarguments suggest that there is reason to believe that national bioethics committees do not actively foster public deliberation on science and technology related issues. It has therefore become apparent from the issues raised by this discussion that we must examine at this juncture what is an ideal mechanism of public deliberation. In other words, if we accept that a national bioethics committee can behave as a mechanism of public deliberation, what would it look like? And what are the ideal circumstances that enable it to facilitate citizen deliberation?

3.2 National Bioethics Committee as a Mechanism of Public Deliberation

The objective here is to outline, in effect, the characteristics of an ideal independent advisory body that constitutes a focal point for public debate (see table in appendix).¹² Drawing from the literature on national bioethics committees, an ideal committee would consequently be a corporate group created on an *ad hoc* basis that examines, analyzes and prepares reports as well as recommendations to government.¹³ There are several advantages to *ad hoc* committees. Firstly, they have the capacity to focus public attention on a particular problem.¹⁴ They have independence from dominant permanent agencies, which is an important characteristic.¹⁵ They have the ability to diversify their interests and points of view.¹⁶ They are effective in enlisting professionals with national and international reputations, and they are effective at creating public pressure for governmental action.¹⁷ A bioethics committee with an indeterminate

mandate would suggest that problems have become substantively and politically more complex and difficult to analyze.¹⁸

Operationally, it must last no longer than four years (as long as the executive) and it must focus on a discrete task.¹⁹ By discrete, it is meant that the committee must have a narrow scope of inquiry well defined in advance.²⁰ An ideal committee must also be official. In other words, it must be created by an executive order or by some form of public inquiry put forth by government.²¹ It must be able to manage issues and restore public confidence in the policymaking process.

Ideally, a national bioethics committee is: 1) to promote transparency; and 2) inform citizens. Both goals can be enforced by legislation. For example, all committees in the U.S. are backed by the Federal Advisory Committee Act (FACA), which requires commissions and committees to have meetings in the open public, solicit public comments on committee publications, and place notices of meetings in the *Federal Register*.²² FACA also requires committees to release specific information to the public, and to conduct open meetings as well as solicit commentaries from the general public. In addition to FACA, committees must also respect the principles behind the Freedom of Information Act (FOIA), which ensures that all citizens have a right to access public government information unless it is exempt by law.

Similar laws exist in Canada. For example, the federal statute on the *Access to Information Act* permits Canadian citizens to ask for documentation of public institutions. Overseeing such legislation at the national level is the Privacy Commissioner of Canada. Canadian provinces also have legislation that oversees the right to access public information. For example, both the provinces of Ontario and Quebec have additional

legislation that ensures the freedom of information. The Ontario provincial government has the *Freedom of Information and Protection of Privacy Act*, which applies to all Ontario's public institutions including agencies, boards, and commissions. In Quebec, the people have the right to access public information via the *Act Respecting Access to Documents Held by Public Bodies and the Protection of Personal Information*.

The idea behind this type of legislation is to have more "open government" according to Sheila Jasanoff.²³ She claims that this kind of legislation is the result of an expanding citizen movement that has become deeply involved in science policy. Especially in the U.S., legal suits and judicial review provisions have caused a sharp rise in the volume of litigation focusing on the relationship between science and policy, and lay people have emerged as an influential participant in the legitimization of science-based regulation.²⁴

In being transparent, advisory committees show: 1) the willingness to make public all of their documents and activities; and 2) the ability to ensure that all public deliberation activities are easily accessible by the general public and that they offer citizens an opportunity to be heard. At present, there is a debate on what should and should not be revealed to the public; dividing transparency into two forms: procedural and substantive.²⁵ An example of procedural transparency is making summaries of minutes available for public display, but keeping the full minutes out of public scrutiny.²⁶ Another example is the idea of providing information regarding a committee's membership and the general procedures of its activities, but not information relating to the activities during member selection. Substantive transparency, on the other hand, does not imply restrictions to any information that relates to topics under review by a

committee. Therefore, whatever work accomplished by a committee that is substantive in nature such as a report or staff paper will be made accessible for public viewing.

However, regulations such as FACA ensure that the public has access to most documents produced by advisory committees, and this includes whether they are procedural or substantive in nature. In such cases, the public has access to committee meeting minutes, to information regarding member selection, staff papers, and other publications such as previous considerations by the committee.²⁷ What is also important is that the general public has an opportunity to discuss these items as well as other concerns relating to a topic under review by committees. This kind of legislation not only enhances public trust in committees, but also shows that it is accountable for its recommendations to government. When committees limit what the public can and cannot have access to, committees make themselves vulnerable to attacks by sceptics.

Another important feature of an ideal national bioethics committee is membership. Membership should be drawn from outside government circles to ensure institutional independence.²⁸ A successful bioethics committee will have members that are representative of various religious, cultural and ethical views. This means members should be professionals as well as ordinary citizens. The selection of committee members should be accomplished in such a fashion that would allow the appointment of professionals from diverse cultural backgrounds and religions. Ideally, an institution other than the executive branch of government would perform the selection of committee members. The use of ad hoc committees to serve as outside interlocutors, could also be extremely useful in the selection of committee members, and could be an indication that efforts to select professionals are not influenced by political interests. Otherwise, the use

of non-partisan expert groups that are not part of the government executive such as academic associations would be promising as well.²⁹ Lastly, the selection of members should be made public in some sort of register to give the public one month to comment on the proposed individuals.³⁰ The government could then use these comments to make necessary changes before a committee's membership is made final.³¹ This would allow the permeation of different opinions, and would reduce vulnerability of many bioethics committees to interests of diverse parties.³²

A final yet important characteristic of an ideal national bioethics committee is the ability to foster public deliberation while respecting the basic principles of liberal democracy.³³ A deliberative approach focuses on qualitative aspects as well as procedural.³⁴ These qualitative aspects are related to substantive concepts of freedom and justice. The normative qualities brought by these substantive concepts add intrinsic value to a well-conducted process of public deliberation.³⁵ A well-conducted process of public deliberation in turn requires procedures.

In an ideal situation, a national bioethics committee will select its own procedures unless stipulated by law. These public deliberation procedures are based on their goals and their rationales for engaging. For example, the PCBE has sought to establish a procedure for public deliberation deeply influenced by the need to develop an understanding on the different perspectives on stem cell research. The process of deliberation adopted by the PCBE was a form of public consultation called public commentary. Public commentary is a session held by the PCBE during its Council meetings. The session is exclusively dedicated to listening to public speakers. The process is recognized as being quite simple. Individuals who wish to address a particular

issue or present a cause before the Council are welcome to attend a commentary session by registering themselves. Since the Council sits only in Washington DC, public speakers are required to travel if they wish to be heard by the Council. Another example is the Canadian Biotechnology Strategy (CBS) that gives CBAC the overall mandate to educate, and consult with the Canadian public on the rapid advances in biomedicine to recognize public attitudes and understandings.

Additionally, an ideal committee must be independent of governmental influences. Independence can be loosely defined as the ability of a bioethics committee to act on its own behalf with regards to setting its own agenda, controlling membership tenure, and be free of exogenous influences.³⁶ An ideal bioethics committee would, firstly, have complete administrative independence from discretionary or arbitrary interference by the executive authority. The committee would be free to make membership appointments, and organising its agenda.

Moreover, bioethics committee membership would be secure. In other words, committee members would have security of tenure, and could only be removed for causes related to the capacity to perform their functions. This would reduce the probability for committee members to be dismissed or replaced without just cause. The dismissal of any member should also be subjected to review by an independent body with reasons for dismissal provided. At a minimum, the legislative branch of government should set committee mandates instead of the executive, and establish independent bodies to oversee committee activities. This would help avoid situations, for example, where the White House would have direct control in exercising the appointment and dismissal of committee members without just cause.³⁷

3.3 Operationalizing Public Deliberation via an Ideal National Bioethics Committee

Having considered the ideal characteristics of a national bioethics committee, the question still remains: how to practically proceed in fostering public deliberation? To accomplish this objective, there must be a process in place. This process must begin with identifying a social problem or a topic that is of national concern. A key consideration for adopting public deliberation is identifying where the issue lies.³⁸ Is it an issue competing for space on the public agenda?³⁹ Alternatively, is the issue at a point where existing policy needs to be updated, or has there been a series of events such as an unexpected crisis or scandal that has given it national attention?⁴⁰ An event like a crisis can bring negative attention to an issue that has normally not been paid any interest.

An issue can also be given importance if focussed on by the media. Governments can also bring attention to a specific issue by debating its place on the policy agenda during a congressional or parliamentary session. A national bioethics committee if publicly mandated can address such an issue. At other times, a national bioethics committee may find that such an issue is of great importance to society and should be examined at all costs.

Since issues of national concern often attract many stakeholders, it is the responsibility of the national bioethics committee to provide a way for all, if not most stakeholders, depending on the subject and situation, to share information and talk about the relevant issues. To identify some potential stakeholders, the European Federation of Biotechnology Task Group on Public Perceptions has put together a list of eight major stakeholder groups that should be identified in any debate involving science and technology. They are: 1) scientists from industry and academia; 2) biotechnology

companies; 3) ethicists and social scientists; 4) politicians; 5) media; 6) non-governmental organisations; 7) professionals (i.e. doctors, legal specialists, religious leaders); and 8) groups within society differentiated by age, culture, religion and education.⁴¹ Before going any further, it is important to note that the European Federation of Biotechnology Task Group on Public Perceptions identifies ordinary citizens as a stakeholder group. The discussion that follows considers this detail and must be read to include lay people.

Once the stakeholders are identified, the next step is for the national bioethics committee to gather facts, hear from concerned stakeholders, consider the wisdom of relevant policies and entertain reasonable appeals.⁴² To do this, the committee must establish when and how it will gather the stakeholders, but before establishing its procedure it is the responsibility of the committee to educate all stakeholders on the subject. This step in the deliberation process is crucial as it makes the issues translatable to others. It also corrects what the public believe is the truth about a particular subject through concept articulation.⁴³ The impact of stakeholder education is also felt at the government level and within professional communities.⁴⁴

Stakeholder education serves, in effect, two purposes. The first is the sharing of information. To maximize information sharing, information on the issue of concern must be free-flowing, complete and balanced.⁴⁵ The second purpose is the framing of the issue being debated. It is imperative that the issue being discussed is framed in a neutral and unbiased manner. This allows the public to discuss the most difficult policy issues facing policymakers.⁴⁶

Once an issue has been identified and framed in a neutral manner, then an ideal national bioethics committee will establish a procedure that determines when and how stakeholders will be allowed to debate the issue. This involves committee members deciding where and how stakeholders can participate in dialogue with experts and policymakers. However, legislation can also establish the procedural details. A good example is the U.S. Human Embryo Research Panel, which had the mandate to establish the manner in which the panel would choose to deliberate with the public at the very outset.

After deliberation has taken place, what is finally required of an ideal national bioethics committee is to obtain feedback on the issue deliberated. Feedback is an important component of public deliberation that is often taken for granted. It can be obtained through deliberative polling and opinion polls, which seek out what the public thinks and how they feel discussions on the issue or how the issue itself is being addressed. This final step is finalized with a synthesis of the arguments that were fleshed out in the debate in a formal report or recommendation to government.

3.4 Potential Variables That Can Hinder Ideal Public Deliberation

Ideal public deliberation is not without certain fallbacks. Public deliberation can surely be hindered by several factors. To simplify this discussion, the variables that could hinder ideal public deliberation are clustered into two categories: 1) obstacles that are related to public deliberation; and 2) obstacles that are related to national bioethics committees. Obstacles that are related to public deliberation involve issues of procedure. In other words, these issues are directly related to the process of public deliberation.

The first and often forgotten obstacle to ideal public deliberation is the lack of information. Ideal public deliberation depends on quality discourse. In order to have quality discourse, all potential stakeholders and citizens must have access to information on the topic of debate. As mentioned above, education on issues, particularly scientific issues, is important. Often, citizens do not feel like they can contribute to a discussion particularly when the subject matter is not within their competency. This is linked with the fact that there is often a lack of feedback from citizens, which has a lot to do with the inability of experts to simplify complicated issues. Another related obstacle is restricted access to public forums. Often ordinary citizens do not have access to public forums. These forums are often limited to stakeholders and experts.

When dealing with barriers relating to national bioethics committees, the issues are can be numerous. Firstly, participation techniques used to foster public deliberation can be inadequate. What this means is that the techniques used are limited to public consulting. These one-way or top-down methods which are often not participant focused or interactive do not encourage activities that involve public deliberation.

The political environment can also have an impact on public deliberation. For example, the conservative government of President Bush left many avenues for the President's Council on Bioethics to explore what American's thought about stem cell research. However, many who have observed the committee claim the conservative perspective supposedly held by a majority of its members limited its potential. Related to this problem is the issue of conflict of interest. There are many professionals and experts that have allegiances to various organisations, and must respect these alliances even when participating on a national bioethics committee.

Given that the path of a national bioethics committee can be diverted in light of its members. Its path can also be diverted due to a lack of institutional independence. A committee that has little power in setting its own agenda is a committee with little independence. Today, it is not uncommon for the executive branch of government to be directly involved in the setting of a committee's agenda, but it should not dictate what the agenda will entail. These principal barriers to ideal public deliberation are confounded by institutional obstacles, such as policy-makers common misperception that the public cannot contribute meaningfully to the policy program development.⁴⁷ In general, contouring these obstacles requires proper planning and effort from the institutional perspective.

3.5 Conclusion

The fact that public bioethics committees are comprised of experts selected and mandated by governments prompts much criticism. Many scholars fear that politics has a great hand in public bioethics committees. Particularly since the appointment of committee members is often not a public process. This is associated with the notion that bioethics committees are created with preconceived opinions reflecting those of the elite, which has inevitably left bioethics committees with a tainted reputation for failing to embrace a whole range of issues that were once part of the agenda of bioethics, and neglecting rigorous rich debate about the philosophical and theological underpinnings of science and technology.⁴⁸

Some believe that the public is bought off through superficial assurances that the “shop is being watched”.⁴⁹ It is plausible that these perspectives stem from the fact that

existing bioethics committees have been created during times of confusion, conflict and open public controversies leading many to question their staying power and whether their constitution has an impact on public deliberation. Particularly during the last several decades where extraordinary changes have occurred in science and technology.

However, there are many scholars who feel that these arguments are unfounded.⁵⁰ They claim that national bioethics committee serve to 'bring the public back' into the policymaking process.⁵¹ To test the foundation of this statement, this chapter has explored what an ideal national bioethics committee looks like and under what circumstances it will effectively and efficiently foster public deliberation. The following ideal features for a national bioethics committee highlight some of the major points fleshed out in this chapter. Firstly, an ideal national bioethics committee must have technical experts. It must be representative of the major stakeholder interests or areas of knowledge involved in the issue. Thirdly, its members must be prestigious and of high status. The committee must also be visible and able to treat a public problem in a public way, and finally, it must be established on an *ad hoc* basis and independent as well as objective in its work.

The next step is to apply both ideal models for a national bioethics committee and public deliberation to real case studies, which have been previously identified as the President's Council on Bioethics and the Canadian Biotechnology Advisory Committee. However, prior to this, it is imperative that we explore the context in which these case studies are analyzed. The next chapter will focus on reviewing the North American stem cell research controversy.

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- ¹² European Federation of Biotechnology Task Group on Public Perceptions, *Who Should Communicate with the Public and How?* The Netherlands, 2003, 7 available at http://files.efbpublic.org/downloads/EU_FW_REPORT_1.pdf.
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- ¹⁸ Thomas R. Wolanin (1975), 125.
- ¹⁹ Amy B. Zegart (2004), 369.
- ²⁰ Ibid.
- ²¹ Ibid.
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⁴⁷ Ibid., 12.

⁴⁸ Udaya Wagle (2000), 210.

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Chapter 4

Reviewing the North American Stem Cell Research Controversy

4.1 Introduction to the Nature of the Stem Cell Research Debate

The usage of human embryos for research purposes has raised considerable ethical, legal, and moral issues. For example, the shortage of good quality embryos for research has put a strain on available stock. To accommodate this shortage, researchers have tried to tap into unwanted or forgotten frozen embryos from private IVF (*in vitro* fertilization) clinics. However, this practice raises considerable consent and confidentiality issues such as should donors and patients that did not give consent for research to be conducted on their frozen embryos at the time of treatment be contacted? What if donors or patients cannot be reached? Who has ownership of these embryos? While these questions are highly relevant, in actual public debate the question on the moral standing of the human embryo has become the most prominent issue and central to the formation of public policy.

Whether the human embryo should have the same status and legal rights as a person is an issue that has been debated for just about four decades starting with the *Roe v. Wade* decision that found that the laws against abortion violated a constitutional right to privacy in the U.S. This decision unleashed a worldwide debate and a movement geared toward understanding the constitution of the human embryo and why it is considered sacred to some and not to others. The most vocal critics against the use of human embryos in stem cell research have been anti-abortionists. However there are many others who have expressed their perspectives such as researchers, feminist groups

and patient advocacy groups representing individuals with Alzheimer's disease, diabetes and other debilitating genetic diseases.

Society has been trying to balance the many competing interests whether they are religious, cultural or scientific. For many, conciliation should be made, but the question of compromising human embryos has proven to inform strong differing views. The following is an account of the debate on the status of the human embryo, which shows that the conflict of interests and beliefs on this issue have been irresolvable.

Arguments from the Pro-Life Perspective

Arguments from the pro-life perspective are complex and multifaceted and like the pro-research view, the issues are centered on the following question: when does human life begin? There are many pro-life perspectives as there are pro-research. The following discussion however will focus on the arguments most heard during the stem cell research debate. For some, life begins at conception when the intrinsic value of human embryos begins.¹ From this point of view, the destruction of life cannot be justified by the means to cure debilitating diseases. For example, the Catholic tradition believes that abortion or destruction of the embryo prior to forty days of development is immoral. The most vocal religious group against the destruction of human embryos is the National Conference of Catholic Bishops and its Canadian counterpart, the Canadian Catholic Bioethics Institute. However, the conservative positions of the NCCB and the CCBI do not reflect all Catholics.² Even the Pope Jean Paul II, although he publicly disapproved Bush's August 9th 2001 policy, did not speak *ex cathedra* about embryo research, which would have made his statement 'infallible' according to Catholic doctrine.

To date, the Catholic doctrine on embryo research is found in The Declaration of the Pontifical Academy for Life dated 25 August 2000, which states the following:

1. On the basis of a complete biological analysis, the living human embryo is – from the moment of the union of the gametes – a human subject with a well defined identity, which from that point begins its own coordinated, continuous and gradual development, such that at no later stage can it be considered a simple mass of cells.
2. From this it follows that as a “*human individual*” it has the *right* to its own life; and therefore every intervention, which is not in favor of the embryo, is an act, which violates that right. Moral theology has always taught that in the case of “*jus certum tertii*” the system of probabilism does not apply.
3. Therefore, the ablation of the inner cell mass (ICM) of the blastocyst, which critically and irremediably damages the human embryo, curtailing its development, is a *gravely immoral* act and consequently is *gravely illicit*.
4. *No end believed to be good*, such as the use of stem cells for the preparation of other differentiated cells to be used in what look to be promising therapeutic procedures, *can justify an intervention of this kind*. A good end does not make right an action which in itself is wrong.

For Catholics, this position is explicitly confirmed by the Magisterium of the Church which, in the Encyclical *Evangelium Vitae* states that:

“The Church has always taught and continues to teach that the result of human procreation, from the first moment of its existence, must be guaranteed that unconditional respect which is morally due to the human being in his or her totality and unity in body and spirit: ‘The human being is to be respected and treated as a person from the moment of conception; and therefore from that same moment his rights as a person must be recognized, among which in the first place is the inviolable right of every innocent human being to life.’”³

Protestant traditions seem to vary depending on the denomination. Historically, Protestantism supported science believing that nature is faulty and that God intended us to discover its inner working and to correct them.⁴ Protestant sects supporting this view include the General Assembly of the Presbyterian Church and the United Church of Christ. Denominations that have taken value laden conservative approaches include the Missouri Synod Lutheran Church, the Southern Baptist Convention and the United Methodist Church, all three of which oppose embryonic stem cell research.⁵

These views examine the human embryo as an independent organism, which has the potential and the capacity to live and breathe like human adults and infants. For example, for Protestants it is clear that one need not be actually conscious, reasoning, deliberating, making choices, etc., in order to be a human being who deserves full moral respect, for it is clear that people who are asleep or in reversible comas deserve such respect.⁶ Only adverse complications can reverse these capabilities. From this perspective, we can see that human embryos have the capacity to gain the abilities that adult humans have.

However, you don't need religion to tremble at the thought of unrestricted embryo research.⁷ According to Charles Krauthammer, columnist for the Washington Post, "you simply have to have a healthy respect for the human capacity for doing evil in pursuit of the good."⁸ This critical view of stem cell research is situated within a broader critique of science and the notion of 'technological progress'. Scientific progress is criticized not on religious beliefs but rather on the belief that new technology can be destructive to humans and the environment and that science is a manifestation of 'man's' continual need to control nature.

Arguments from the Pro-Stem Cell Research Perspective

Alternatively, there are those who argue that the moral status of the human embryo is more graduated and that there is discontinuity from conception to the establishment of personhood.⁹ This belief centres on the idea that a human embryo does not have the characteristics of a human being and should therefore not bestow the same rights. However, some believe that the destruction of the embryo is immoral only before the 14th day after conception, because until then cell division of the embryo has not

finalized. For example, the Jewish tradition does not ascribe moral status to an embryo at the time of fertilization, because it is believed in this tradition that during the forty days of its development, the embryo is like water.¹⁰ This view is analogous to a centuries-old tradition of ‘ensoulment’, which according to Thomas Aquinas, occurs in males at 40 days and at 90 days in females after conception, thereby establishing personal existence and completing the process of conception.¹¹

The Jewish tradition also places a strong emphasis on the saving of life. According to Laurie Zoloth, a conservative Jewish scholar, it is mandated in the Jewish tradition to save life. The following is an excerpt from her testimony before the National Bioethics Advisory Commission (NBAC):

“The task of healing in Judaism is not only permitted, it is mandated. This [viewpoint] is supported and directed not only in early biblical passages (“you shall not stand idly by the blood of your neighbor,” and “you shall surely return what is lost to your neighbor”), but in numerous rabbinic texts as well. The general thrust of Jewish response to medical advances has been positive, even optimistic, linked to the notion that advanced scientific inquiry is a part of *tikkun olam*, the mandate to be an active partner in the world’s repair and perfection.”¹²

Similarly to Jewish tradition, Islamic dogma places ‘ensoulment’ at the 120th day, and holds that a very early embryo has no moral status.¹³ However, the Koran is silent with regards to the status of the human embryo. In a statement made before NBAC, Islamic scholar Sachedina summarized the Islamic position on the use of human embryonic stem cells for research:

“[O]n the basis of all the evidence examined for this testimony, it is possible to propose the following as acceptable to all schools of thought in Islam: 1. The Koran and the Tradition regard perceivable human life as possible at the *later* stages of the biological development of the embryo. 2. The fetus is accorded the status of a legal person only at the later stages of its development, when perceptible form and voluntary movement are demonstrated. Hence, in earlier stages, such as when it lodges itself in the uterus and begins its journey to personhood, the embryo cannot be considered as possessing moral status. 3. The

silence of the Koran over a criterion for moral status (i.e., when ensoulment occurs) of the fetus allows the jurists to make a distinction between a biological and a moral person, placing the latter stage after, at least, the first trimester of pregnancy.”¹⁴

Arguments from other pro-research perspectives suggest that since people frequently do not grieve, or do not grieve intensely for the loss of an embryo early in pregnancy, as they do for the loss of a fetus late in pregnancy or of a newborn being worthy of full moral respect, then the human embryo should not be morally respected.¹⁵ The basis for this argument is that people are generally told that there is no human being until there is movement within the womb or ‘quickening’. In the same vein, it is argued that emotional attachment is little to non-existent during early pregnancy, and therefore, a human embryo should not be respected morally. Many pro-life advocates will argue that the lack of emotional bonding is insufficient to justify the destruction of human embryos for the purpose of research, but there are many who are moved to believe that human embryos are not worthy of moral and legal status because a high percentage of embryos formed in natural pregnancies fail to implant or spontaneously abort.¹⁶ Concomitantly, there are people who believe that the importance of relieving suffering outweighs the need to protect human embryos.

The argument for conducting research using human embryonic stem cells is rooted in the ideals of freedom of thought, freedom of conscience, and specifically in this context- the freedom of inquiry.¹⁷ Supporters of this view believe that current human embryonic stem cell policy which restricts research breach these principles, and while the state is not obligated to fund research, it is this stance that has pitted pro-research groups against pro-life supporters. Many believe that interest groups have taken on the role of

informing and influencing the type of policy adopted. In the stem cell debate, their influence and strength were forged through coalitions. For example, Thomas Banchoff reports that over the 1998-2004 period, scientific associations with proven success in lobbying governments took up the stem cell issue and forged alliances with biotechnology and biomedical companies seeking eventual profit from genetic and regenerative medicine, and with patient advocacy groups seeking eventual cures for victims of degenerative diseases.¹⁸ These groups were countered primarily by religious pro-life groups opposed to the destruction of human embryos on moral and ethical grounds.¹⁹ This very open and public debate has left policymakers confronted with a very anxious public weary about destroying embryos for research purposes.

4.2 The History of Stem Cell Research Policy

The scientific view stands in sharp contrast to the various religious perspectives that generally define a human being as “a miraculous act of divine creation.”²⁰ These two distinct understandings have struggled for authority within the realm of policy making.²¹ In the U.S., the very question of killing human life has created the deepest moral divide. In response to public concerns raised after the passage of the *Roe v. Wade* decision, the U.S. Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (NCPHS).²² The Commission proposed a principal of equality of treatment for fetuses brought to term and those aborted.²³ In 1978, the Commission published the Belmont Report, a document that identified ethical principles applicable to research on human subjects.²⁴

The revisiting of this question since the abortion debate has also re-opened old wounds for many Americans.²⁵ Between the 1970s and the 1990s, many other advisory bodies examined the issue of using human embryos for research. The first committee to recommend that research on embryos be allowed was The Ethics Advisory Board (EAB) of the U.S. Department of Health, Education, and Welfare. It suggested that with the consent of gamete providers, remaining embryos from IVF treatments could be frozen, discarded, or donated to others for research.²⁶ However, the U.S. Congress did not agree with the recommendations of the committee and initiated a fifteen-year ban on research using human embryos. This ban stood until 1994, when the National Institutes of Health (NIH) director Harold Varmus convened on the Human Embryo Research Panel (HERP). This was the second committee that came to the conclusion that research on embryos created for IVF (*in vitro* fertilization) should be funded. In response to this recommendation, the NIH began to set up funding guidelines to start awarding monies for embryo research, but before any grants were awarded, the US Congress intervened and added the Dickey Amendments to the Health and Human Services appropriation bill, which stated that “no funding would be available for the creation of human embryos for research or for research involving human embryos that are ‘destroyed, discarded, or knowingly subjected to risk of injury or death’.”^{27,28} As per the NIH-funded research, this provision barred (a) fertilization, cloning and parthenogenesis; (b) derivation of human embryonic stem cells by any embryo-destructive means; and (c) studies of human embryonic stem cells derived by any embryo-destructive means.²⁹

However in 1998, the discussion was ignited again when biomedical researchers successfully isolated pluripotent stem cells forcing President Clinton to seek advice from

the recently formed National Bioethics Advisory Commission (NBAC), which was mandated to investigate the issue.³⁰ NBAC reported that federal funds should be made available for research, however, the fact remains that any policy permitting public funding for stem cell research permits the destruction of human embryos. Many have argued for a disassociation between the moral status of the human embryo and the issue of public funding, but on August 9th, 2001 President Bush endorsed a policy that would forever link the two. Attempting to reach a compromise between religious moral beliefs and the need for research, President Bush permitted NIH funds for research on existing destroyed stem cell lines left over from IVF treatments. Research on viable human embryos after this date is not permitted. This policy also supports the banning of federal funds for research on embryos, fetuses, and embryonic or fetal tissue, while permitting largely unregulated research in the private sector.³¹

In 2004, the U.S. Congress revisited this issue after several congressmen pledged their support for biomedical research, particularly stem cell research. By 2005, the Stem Cell Research Enhancement Act was proposed by Congress. It aimed to amend the Public Health Service Act to require the Secretary of Health and Human Services to conduct and support research that utilizes human embryonic stem cells, regardless of the date on which the stem cells were derived from a human embryo, provided such embryos: (1) have been donated from in vitro fertilization clinics; (2) were created for the purposes of fertility treatment; (3) were in excess of the needs of the individuals seeking such treatment and would never be implanted in a woman and would otherwise be discarded (as determined in consultation with the individuals seeking fertility treatment); and (4) were donated by such individuals with written informed consent and without any

financial or other inducements.³² The bill passed through Congress and the Senate; however it was vetoed by the President upon receipt stating, “[this] second bill [proposed by Congress] attempts to overturn the balanced policy I set. This bill would support the taking of innocent human life in the hope of finding medical benefits for others. It crosses a moral boundary that our decent society needs to respect.”³³

In Canada, stem cell policies emerged in response to a growing number of inquiries from Canadian researchers who questioned whether embryonic stem cell research could be publicly funded. The debate surrounding this inquiry led to the creation of an ad hoc Working Group on Stem Cell Research formed by the Canadian Institutes of Health Research (CIHR) to address the issue.³⁴ The Working Group’s purpose was to temporary fill a regulatory vacuum by developing guidelines relative to publicly funded stem cell research. Together with the Natural Science and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC), the CIHR developed an important policy statement titled *Tri Council Policy Statement: Ethical Conduct for Research Involving Humans* (1998) which provided guidance as to what types of research involving human pluripotent stem cells could be publicly funded.³⁵

The CIHR later adopted additional guidelines, which permits the harvesting of stem cells from “spare” embryos created by in vitro fertilization. However, given the sketchy ethical framework in this area, the CIHR additionally set up the National Stem Cell Oversight Committee to provide ethical review of all CIHR funded research involving human stem cells.³⁶ While both policies represented milestone efforts to guide

stem cell research in Canada, it is also known that these guidelines have little regulatory power especially in the private sector.

To fill this policy void, the Canadian Government presented legislation on *Assisted Human Reproduction* in May of 2001. At the same time, the Parliamentary Standing Committee on Health presented its research in support of the draft legislation as regards to the use of embryos for stem cell research. It was not until March 2004 that the *Assisted Human Reproduction Act* successfully passed through the House of Commons and the Senate. In large part, the Act prohibits a number of activities, including: reproductive and therapeutic cloning, the creation of embryos for research purposes, germ line alterations, non-medical sex selection and commercial surrogacy.³⁷ Until now, the Canadian view is to control the private sector and how it conducts research on human embryos. Recently, the CIHR updated its guidelines to respond to the rapid advances in this research area. The revised policy on stem cell research includes the establishment of a national registry of human embryonic stem cell lines created in Canada.

4.3 Tracking the National Debates on Stem Cell Research I: The President's Council on Bioethics (PCBE)

The PCBE is an *ad hoc* committee that was created by a presidential executive order during a tumultuous public debate on stem cell research. The Council is composed of eighteen formally appointed members personally selected by the President. All the members come from various backgrounds including religion, ethics, metaphysics, moral philosophy, medicine, law, political theory, public policy, and biology. Leading the Council is chairman Edmund D. Pellegrino who has recently succeeded Leon Kass in this role. Together, the members of the PCBE were commissioned to address all matters

relating to biomedicine, in particular stem cell research, and to raise a national debate on the issues as well as report their findings to the President.

The status of the human embryo is a question that has also been a source of disagreement among experts. According to former PCBE member William May, the embryo status question surfaced on many occasions during PCBE deliberations.³⁸ From his account three responses or arguments emerged from the council's deliberations:

Argument 1: The status of the human embryo is not just a "clump of cells" but an integrated, self-directing developing whole, capable [...] of the continued organic development characteristic of human beings.³⁹ In other words, the microscopic material in a petri dish is considered as "one of us".⁴⁰

Argument 2: The use of human embryos for research presents no special moral problem since human embryos have no status because human embryos lack any trace of a nervous system.⁴¹ They have no conscience to suffer physical pain, which spells the difference between human life that is worthy of respect and that which is not. To illustrate this point further, Elizabeth Blackburn, former Council member expressed disappointment with the Council's decision on a moratorium, saying, "To prohibit or cripplingly regulate any of the ways in which embryos can be manipulated is tantamount to saying that the embryo must be afforded tightly regulated "rights". I find this disturbing, as it is potentially dangerous to valuable scientific stem cell research."⁴²

Argument 3: The status of the human embryo is intermediate and it is therefore neither a full human nor a mere thing.⁴³ Another former council member, Francis Fukuyama, spoke about his role on the council and on this particular issue after the drafting of the report *Human Cloning and Human Dignity*. His position on the status of the human embryo was and still remains what he and several other scholars call an

intermediate perspective. According to Fukuyama, “full moral status is something is that is acquired with time.”⁴⁴ Moreover, the acquisition of this status continues throughout life. Therefore, there are, according to Fukuyama, no moral objections toward the use of human embryos for research as long as it is socially regulated.

What these arguments represented for the Council was the beginning of a discussion that according to some scholars alienated members of the council including Elizabeth Blackburn. However, other observers were more concerned about the possible exclusion of the public in these discussions even though Leon Kass, then chair of the council, reassured the public at many occasions that the council’s work consisted of creating a national debate on stem cell research. For example, during a lecture delivered at the annual meeting of the American Society of Bioethics and Humanities in Philadelphia, Leon Kass stated that “We [the council] have sought out viewpoints not represented on the Council through reading and invited testimony and through public comment, oral and written.” He also stated that:

“We [the council] aspire to a richer bioethics, debating ends as well as means, and self-consciously committed to articulating the full range of human goods that we are eager to promote and defend; and we aspire to address the President and the polity on clearly political issues-issues important to the polity as a whole- and not merely administrative or regulatory ones, and we aspire to do so in the ordinary terms of public discourse.”⁴⁵

However, scholars have questioned the existence of this so-called national debate on stem cell research. Correspondence from science, policy, and bioethics journals paint a different picture than what the chairman expressed in his lectures. Leonard Zon, Laurie Zoloth and Suzanne Kadereit wrote in a correspondence piece in *PloS Biology* in June of 2004 that,

“The original recommendation of the President’s Council on Bioethics was a four year moratorium on stem cell research. The purpose of this moratorium was theoretically to open a large, national discourse on the topic of stem cell research, a debate intended to bring all sides into thoughtful reflection on the issue. To that end, the International Society for Stem Cell Research (ISSCR) has repeatedly and consistently offered an open forum for all side in the debate at our conferences, and has carefully offered invitations to join our society and to speak at our annual meeting to members of the President’s Council, including colleagues whose opposition to stem cell research has been clear. None have accepted. Dr. Kass, in particular, has received several direct appeals but has turned down every such opportunity to make his case to the researchers who arguably are his discourse partners, from whom he could learn much, and whom he should be actively engaged in teaching.”⁴⁶

In the same issue, Daniel Perry expressed concern that “there is a small number of researchers on the council and a lack of scientific data being presented to policy makers. [Also], with the exception of public comment periods, patient organizations have no voice in the work of the council as it discusses issues that profoundly impact them.”⁴⁷

However, Kass points out that the intent to start a national discussion on the issue of stem cell research and to encourage reflection upon the ethical and social issues surrounding this biomedical technology was an ambitious endeavour. For starter, fleshing out the different perspectives on the use of human embryonic stem cell lines for research involves fostering a dialogue with an educated public. Those individuals who had the privilege and opportunity to speak before the council were well informed on the debate and represented individuals that share similar perspectives. For example, on June 12th, 2003 Michael Manganiello, President of the Coalition for the Advancement of Medical Research presented his arguments in support of the use of human embryonic stem cell lines for stem cell research.

During that same session, Richard M. Doerflinger, Deputy Director and Secretariat for the Pro-Life Activities of the U.S. Catholic Bishops Conference presented

his arguments on behalf of his organisation against the destruction of human embryos for research. Other speakers included Maxine F. Singer, Chair of the Committees on Science, Engineering, & Public Policy, National Academies, and Michael J. Werner, Vice president of Bioethics, Biotechnology Industry Organization who represented various views. It is also important to point out that patient organisations were represented during these meetings. On June 3rd, 2003, Pamela Madsen from the American Infertility Association spoke before the council, as well as Tricia Brooks from the Christopher Reeve Paralysis Foundation, and Charles Queenan, an ordinary citizen who spoke to the council on behalf of his daughter who suffers from juvenile diabetes to discuss the potential benefits of stem cell research that could help his daughter and millions like her. These are just a few examples of those who showed their support or disapproval for stem cell research.

Leon Kass claims that these opinions were all represented in the council discussions. This point is especially important since the council was never mandated to reach a consensus but to start a national dialogue on the relevant issues. In theory, a national debate involves respect for other opinions, reciprocity and common courtesy. Kass argues that the general principles of deliberation were respected, and that the council “contributed to a much wider public debate about stem cell research than occurred before [the council] started its work”.⁴⁸ Moreover, a proper bioethics must lead reflection on the ways in which new biotechnologies may affect those things that matter most regarding how human lives are lived, and this means beginning by reflecting upon the highest human goods and understanding the latest technological advances in this light.⁴⁹

According to Kass, the council's reports such as *Human Cloning and Human Dignity* in which the council explores the arguments for and against the use of pluripotent human embryos for research purpose, were instrumental to this national debate on stem cell research. For example, in this particular report the council's goal was to contribute to an understanding of the goods at stake and assess whether they might be balanced against one another by developing the moral case both for and against pursuing research cloning.⁵⁰ This report was mildly received by the academic community mainly because the report was published a year after the president endorsed his policy on stem cells. Included in this report was the proposition of models of public deliberation in order to weigh competing goods.

However, it was not until the publishing of *Monitoring Stem Cell Research* that the Council decided to "convey the moral and social importance of the issue at hand and to demonstrate how people of different backgrounds, ethical beliefs, and policy preferences can reason together about it."⁵¹ In this report, the council provides an update on the scientific and policy developments on stem cells, and appends 10 papers prepared by scholars commissioned by the council to present their thoughts on the research and its implications.⁵² The report also sheds light on the various views on stem cell research and the status of the human embryo, and talks about how the debate is being portrayed in the mass media. In one account, the council describes monitoring stem cell research like watching Niagara Falls, "Not only do scientific reports pour forth daily, as they do in many other areas of research, but a kind of mist rises up for the torrent of news flashes and editorials, making it difficult to separate knowledge from opinion and hope from hype."⁵³

Among other issues, the report addresses questions such as, “Should moral considerations be used to decide what sort of research may or may not be funded? What is the symbolic and moral-political significance of providing national approval, in the form of active support, for practices that many Americans regard as abhorrent or objectionable? [And] how should we discuss these matters, offering encouragement but without misleading or exploiting the fears and hopes of the desperately ill?”⁵⁴

During the Council’s inquiries into the potentials of stem cell research, it found that there were many alternatives to embryonic stem cells. The white paper on *Alternative Sources of Human Pluripotent Stem Cells* is a revised and updated version of a council’s staff working paper in which the council examines whether alternative sources of stem lines could possibly be used for research purposes in an ethically, and morally sound manner. The Council’s main activity in this endeavour was to thoroughly investigate the potential socio-ethical and moral issues surrounding alternative methods of obtaining stem cells. Therefore exploring four broad approaches to deriving stem cells: 1) by extracting cells from embryos already dead; 2) by non-harmful biopsy of living embryos; or 3) by extracting cells from artificially created non-embryonic but embryo-like cellular systems; or 4) by dedifferentiation of somatic cells back to pluripotency.⁵⁵ While examining the strengths and weaknesses of these methods, the council realized that the complexity and novelty of these techniques inevitably make it impossible for it to ensure the appropriateness of use as alternative sources of pluripotent stem cells.

Accordingly, the white paper serves as an initial inquiry, “designed mainly to see whether there are any insuperable ethical, scientific, or practical objections to further consideration of proposals that involve alternative sources of stem cells.”⁵⁶ Like its report

on *Monitoring Stem Cell Research*, the council makes no attempt at proposing recommendations. However, in an earlier report on assisted reproduction, the council recommended that the disposition of human embryos created in fertility laboratories be tracked.⁵⁷ This recommendation would have had an impact on stem cell research, but it was dropped in response to concerns raised by patient advocacy groups because of privacy issues.⁵⁸

4.4 Tracking the National Debates on Stem Cell Research II: The Canadian Biotechnology Advisory Committee (CBAC)

The stem cell debate reached a similar peak in Canada. Unlike the PCBE, CBAC is a committee with permanent status, and is composed of twenty-one volunteer members from various disciplines that rotate between sessions. The members are selected based on personal attributes and are nominated through a public process that includes a review by the Biotechnology Deputy Minister Selection Panel. From this point, recommendations are made to the Biotechnology Ministerial Coordinating Committee, which then makes the final selection.

CBAC is also known for being a permanent fixture of the Canadian bureaucracy. It behaves much like a policy committee as it makes recommendations to government but also serves as a legitimizing mechanism via its public consultations activities. For example, since its creation, CBAC has developed a 'dialogue tool', which aims to reconcile various views on genetically modified foods in Canada. The dialogue tool travels across the country and gauges Canadians views of genetically modified foods

(GMOs). To date, the ‘dialogue tool’ has only been used for environmental and health issues relating to GMOs.

The first address on the stem cell issue by CBAC was provided by the research of Lori Knowles from the Hastings Center. Her report on the *Comparative Primordial Stem Cell Regulation: Canadian Policy Options* addressed the ethical, legal and policy issues surrounding the stem cell debate in Canada and worldwide. The document also analysed and compared the various international approaches that have been used to address the stem cell regulatory question and to see whether there were any appropriate frameworks that could fit Canada’s needs. While this report did not purport any recommendations, it was commissioned as a preliminary approach towards evaluating a controversial subject.

Realizing that the report would be the first initial step into a national debate on stem cell research, CBAC created an internal Project Steering Committee on New Genetically-Based Interventions of which the focus would be on cloning, stem cell research and xenotransplantation. This Project Steering Committee produced in 2001 a memorandum to the Biotechnology Ministerial Coordinating Committee (BMCC) titled *Stem Cells: Opportunities and Challenges*, which proposed the following:

1) BMCC take note of recent discoveries pertaining to stem cells and the international trends in policy development arising from them; 2) Canada establish a broad framework of regulation pertaining to ARTs (assisted reproductive technologies), including embryo research, that addresses the scientific, ethical and social issues raised by primordial stem cell research and that it is readily adaptable to new discoveries and to experience gained in the application of the new technologies; and, 3) as an interim step, current guidelines pertaining to research involving embryos and fetuses be reviewed and revised as necessary or desirable to take account of recent and projected scientific and technological advances related to primordial stem cells.⁵⁹

Interestingly, many of the experts who presided on the Steering Committee were also involved in the CIHR ad hoc Working Group on stem cell research. On March 29th,

2001, the CIHR Working Group on Stem Cell Research posted a discussion paper on the CIHR website for public consultation and commentary for three months. This approach was seen by the Working Group as a significant way to obtain input from a wide range of stakeholders. The main issues of concern involved the use of public funds for research, alternative sources of pluripotent stem cells, donor consent and of course the moral status of the human embryo, however, seeing that this issue was previously discussed in the 1993 report by the Royal Commission on New Reproductive Technologies⁶⁰, the Working Group wanted to strictly focus on the legality of research, and the various methods of extracting stem cell lines which may be deemed ethically acceptable for government funding.

The debate that flourished from this discussion paper revealed a range of perspectives and opinions on the ethical implications of public funded stem cell research. For example, The Evangelical Fellowship of Canada's response to the discussion paper was supportive and endorsed the proposed moratorium on funding research that involves practices to create human embryos for research, somatic nuclear cell transfer, and research that combines human cells with animal cells. In a similar fashion, the Canadian Physicians for Life, Life Canada, and the Canadian Alliance called for an outright ban on the use of human embryos for research. However, a poll taken by Pollara that questioned 1,700 adult Canadians showed that more than 80 per cent wanted a national regulatory body to oversee the research but 86 per cent said that it's acceptable to take stem cells from donated human embryos while 22 per cent adamantly opposed such a practice.⁶¹

The Working Group received a total of 116 responses 27 of which were from special interest groups, professional groups, health charities, or government agencies, and

89 were from individuals.⁶² In its final report that culminated the public deliberations, the Working Group touched upon many of the themes that emerged from the public deliberations. Many respondents were concerned that allowing publicly funded stem cell research using human embryos would lead scientists down a slippery slope towards cloning, gene therapy or even eugenic selection. Some respondents recognized the need for an overseeing regulatory body for the public and private sectors, while other respondents worried about the potential conflict of interest since many of the researchers participating on the Working Group had close ties with the stem cell research community.

4.5 Conclusion

This chapter traced the North American stem cell research controversy showing that the potential benefits of stem cell research are praised to have unlimited possibilities, but the science, has nevertheless been haunted by public and political backlash since the derivation of stem cells involves the destruction of human embryos. From this discussion it has become clear that genetic technologies such as stem cells carry with them controversial ethical and moral issues, which have generated strong opposition.

Also, this chapter has pointed out that lay concerns about the new genetics are typically broader, often reflecting anxieties about the radical extension of human health and the dehumanizing tendencies of gene technologies. It is therefore not surprising that citizens are concerned by the potential risks generated by such technologies.⁶³ These issues therefore carry emotionally charged moral perceptions, which had an impact in both the U.S. and Canada. The next chapter will build on the discussion of this chapter to analyze national bioethics committees as mechanism of public deliberation.

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Chapter 5

Analyzing the Case Studies

5.1 Introduction

Whether the human embryo should have the same status and legal rights as a person is an issue that is continuously debated. Most of the public controversy in the United States and in Canada has focused on the issue of embryo use and destruction.¹ For example, in the U.S., the very question of “killing” human life for research has created the deepest moral divide which is often compared to the 1973 decision by the U.S. Supreme Court in the *Roe v. Wade* trial. This decision by the US Supreme Court was not widely accepted, and in response to public concerns raised by the passage of this decision, the U.S. Congress created the National Commission for the Protection of Human Subjects of Biomedical and Behavioural Research (NCPHS).² The Commission proposed a principal of equality of treatment for fetuses brought to term and those aborted.³ In 1978, the Commission published the Belmont Report, a document that identified ethical principles applicable to research on human subjects, which supported its initial statement.⁴

Between the 1970s and the 1990s, many other advisory bodies examined the issue of using human embryos for research. For example, the first committee to suggest that research on embryos should be allowed was The Ethics Advisory Board (EAB) of the U.S. Department of Health, Education, and Welfare. It suggested that with the consent of gamete providers, remaining embryos from IVF (*in vitro* fertilization) treatments could be frozen, discarded, or donated to others for research.⁵ However, the U.S. Congress did not agree with the recommendations of the committee and initiated a fifteen-year ban on

research using human embryos. Not until 1994, when the National Institutes of Health (NIH) director Harold Varmus convened on the Human Embryo Research Panel (HERP), was there another committee that came to the conclusion that research on embryos created for IVF should be funded. In response to this recommendation, the NIH began to set up funding guidelines to start awarding grants for embryo research, but before any grants were awarded, the US Congress intervened and added the Dickey Amendments to the Health and Human Services appropriation bill. These amendments banned funding that would provide for the creation of human embryos for research and for research involving human embryos.

In 1998, this debate was re-ignited when biomedical researchers successfully isolated pluripotent stem cells forcing former President Clinton to seek advice from the recently formed National Bioethics Advisory Commission (NBAC) to investigate the issue.⁶ NBAC reported that federal funds should be made available for research, however, the fact remains that any policy permitting public funding for stem cell research, permits the destruction of human embryos. This debate was transposed to the PCBE's discussions on the status of the human embryo, and in the report *Human Cloning and Human Dignity* the committee presents three different positions. The first is the majority view that holds that the human embryo is human and therefore "one of us". The first minority view claims that the "human embryos develop intermediate moral growth that the human embryo has a moral status somewhere between that of ordinary human cells and that of a full human person."⁷ The second minority position claims that the use and destruction of human embryos presents no moral problems because embryos do not have moral status. The way the discussions transpired leads many scholars to believe that

the minority views were not properly considered and respected by the majority, but this perspective is one-sided. In its discussions and reports, the PCBE does respect and discuss the variety of views held by stakeholders and the public alike.

In Canada, the stem cell debate is distinguishable from that of the U.S. The socio-ethical and legal debate in Canada about research on embryos can be traced to the 1993 Royal Commission on New Reproductive Technologies. The Royal Commission was a group of formally appointed experts from a range of backgrounds (i.e. science, law, and ethics) with a mandate to listen to stakeholder testimonies on the issue of reproductive treatments such as in vitro fertilization, and analyse the situation and report its findings. While the report mainly treated new reproductive technologies, it was clear that a policy void on the stem cells existed. This situation, however, was not to last for much longer.

Like in the U.S., the general public questioned the moral status of the human embryo. Religions and advocacy groups held positions that reflect those values supported by their American counterparts. The policy void however created uncertainty around the use of human embryos for research. In response to a growing number of inquiries an ad hoc working group was formed by the Canadian Institutes of Health Research (CIHR) to address the issues.⁸ The group's purpose was to temporary fill a regulatory vacuum by developing guidelines relative to stem cell research. Together with the Natural Science and Engineering Research Council (NSERC) and the Social Sciences and Humanities Research Council (SSHRC), the CIHR developed an important policy statement titled *Tri Council Policy Statement: Ethical Conduct for Research Involving Humans* (1998) which provides guidance as to what types of experiments involving human pluripotent stem cells should be funded.⁹ As concerning embryonic stem cell research these guidelines are

very thin, and for this reason the CIHR has adopted additional guidelines, which permits the harvesting of stem cells from “spare” embryos created by in vitro fertilization, and given the sketchy ethical framework in this area, the CIHR has created a National Stem Cell Oversight Committee to provide ethical review of all CIHR-funded research involving human stem cells.¹⁰ While both policies represent milestone efforts to guide stem cell research in Canada, it is also known that guidelines have little regulatory power especially in the private sector.

To cover this middle ground left unregulated, the Government of Canada in May of 2001 drafted legislation on *Assisted Human Reproduction* in response to a memorandum made by CBAC. At the same time, the Parliamentary Standing Committee on Health presented its research in support of the draft legislation as regards to the use of embryos for stem cell research. It was not until March 2004 that the *Assisted Human Reproduction Act* successfully passed through the House of Commons and the Senate. In large part, the Act prohibits a number of activities, including: reproductive and therapeutic cloning, the creation of embryos for research purposes, germ line alterations, non-medical sex selection and commercial surrogacy.¹¹ However, the general premise is to protect the health, safety and human dignity of all Canadians. Until now, the Canadian view, in general, is to control the private sector whose main preoccupation is to conduct research on human embryos and the derivation of stem cells with *the Assisted Human Reproduction Act*, while at the same time guiding publicly funded research on embryos with the guidelines of both the Tri-Council and the CIHR.

In both the U.S. and Canada, the issue of human embryo destruction for research purposes created social and political divisions on the course of government action. To get

a better understanding of the issues and how citizens feel about stem cell research, both the PCBE and CBAC were commissioned to foster public deliberation on the subject. The first major task bestowed upon the PCBE after its creation was to examine the ethical, legal and social issues associated with stem cell research and related technologies.

To gather information on how the public views stem cell research, individuals came before the committee to talk about their perspective on the stem cell issue and the status of the human embryo. The transcripts from meetings reveal that a majority of the individuals who did speak before the committee represented religious associations, bioethics and professional associations, and patient advocacy groups. Scientific organisations were not represented and less than a handful of ordinary citizens made the trip to discuss the issues with the committee. The lack of representation from these latter groups is due to the fact that the committee does not “go out” to get public views. It waits for the people to come to them.

The main claim by critics is that these meetings were not open to ordinary citizens, and that whatever views garnered during these sessions is reflective of a skewed perspective on stem cell research. CBAC, on the other hand, has a three-step process in its deliberative function. The first rounds of discussions are usually with experts from the area under discussion. This step involves the identification of the various issues that need clarification. The second round of discussions usually involves interested stakeholders. This phase is concluded with the release of a report containing draft recommendations. The final round entails the distribution of the report to all Canadians for a nationwide discussion on the topic and draft recommendations. In all of the phases, the committee

uses discussion methods such as roundtables, citizen forums, and citizen panels and travels across the country to reach as many citizens as possible. However, sceptics claim that the second round of discussions were limited to experts, researchers and policymakers, and that much of the debated from framed in an expert perspective.

5.2 The President's Council on Bioethics and Public Deliberation on the Ethical, Legal, Social and Moral Issues Surrounding Stem Cell Research in the United States

At the time of the PCBE's creation, there was a tumultuous public debate about stem cell research in the United States. The successful cloning of Dolly the sheep was the catalyst for stem cell research becoming a policy priority for the White House. However, there is much criticism about the timing of the PCBE's creation. Some critics claim that President Bush had already made public the Administration's position on stem cell research-that is a ban human cloning and the use of new human embryonic stem cell lines for research purposes. This according to critics made the PCBE look more like a window dressing committee than a policy initiative committee.¹²

However, the PCBE was still responsible for raising public awareness and creating a national debate on the social impact of stem cell research. These activities were required by FACA but were also a *raison d'être* of the Council. The primary intent of the PCBE was to, firstly, inform the public about stem cell research and the potential implications of conducting this type of research in the U.S., and secondly, consult with the public. In a previous chapter, I discussed how the PCBE chose to engage the public in a national debate about stem cell research through a process called public commentary. This process involved stakeholders who would present themselves before the Council and

offer their opinions, positions or discuss in brief how their lives or the lives of loved ones would be affected by stem cell research.

The goal of public commentary was to sensitise the Council members to a range of public views. What is evident about the process used by the Council is that it was speaker oriented. There was no dialogue between the experts and citizens. Nor was there any dialogue between the citizens present at the sessions. What is also interesting is that the Council rarely asked questions during these sessions, and what can be noted from the start is the fact that the speakers who were most often present were representatives of stakeholder organisations. Very few speakers were ordinary citizens. These preliminary observations about the process of deliberation used by the PCBE reveals some interesting facts about how the Council saw the involvement of the general public in stem cell research policy. The discussion that follows examines in more detail how the public was informed, and took part in the analysis of the issues surrounding stem cell research by the PCBE.

According to deliberative theory, knowledge exchange is a process that is continual in public deliberation. It implicitly recognizes that sharing information requires standardization in the language with which the exchange is taking place. It is imperative that the audience is able to understand what is being discussed. This simple and yet significant detail can hamper a very promising knowledge exchange effort.

The literature on knowledge transfer claims that there are several ways to share information, but three methods stand out more than others for their rate of success and ingenuity. The first option is to publish documentation containing information on the issue being debated. The second option, which is a new yet effective way to

communicate, is the development of a web site. The final and third means of translating information to the general public is through face-to-face communication.

In the U.S., the Federal Advisory Committee Act requires all public committees to disseminate information about the issues being addressed by public committees. The general role of FACA is to ‘open’ government to the public however; critics have found that FACA has many pitfalls and loopholes. In fact, the main problem with the legislative framework on public engagement in the U.S. is that it limits just as much as it enables communication with the public. For example, FACA supports activities that foster communication with the public. However, it also establishes administrative barriers. FACA is applied to all committees that are utilised by the federal government however; a committee can be exempt from sharing information with the public if it meets the terms found in the Freedom of Information Act (FOIA). The only recourse available is judicial review. These events can impede public engagement and instead encourage communication with a more privileged public.

This makes clear that there are impediments to communicating with the public in the U.S. However, the PCBE does not fall under FOIA and has instead shared much of its reports, and staff papers via a public website and publications. At an American Society of Bioethics and Humanities Conference, Leon Kass, former chairman of the PCBE, supported this fact by describing at great length to what degree the Council has tried to communicate with the public. Kass states, “The Council’s website is highly used. And three of our publications have been re-published by commercial publishers with the express goal of getting them into circulation for college and university teaching.”¹³

It is interesting that these publications were re-printed for college and university teaching. In fact, approximately 13,000 copies of its reports were sent out over three years.¹⁴ This is an important fact as it points out as the Council's publications are directed at an educated public. For example, *Monitoring Stem Cell Research* is a lengthy volume that reviews the ethical, legal, policy, moral and social issues surrounding stem cells, and while it covers a review of all the relative issues, the language and style used is at a level well above what the average American normally reads. What can be considered as an adequate level of writing for the average American is a high school level or the style generally similar to that used in newspapers and magazines. Unfortunately, FACA does not regulate the content of documents made available to the public. As a result, most of the Council's publications except one white paper on *Alternative Sources of Human Pluripotent Stem Cells* are lengthy documents written clearly for an academic and expert audience. While the Council offers summaries of its reports on its website, it fails to offer information at a level acceptable for the lay public.

The lack of information being disseminated to the general public has a lot to do with how the PCBE framed the stem cell research debate. During its meetings, the PCBE's interaction with policy makers, decision makers, health, ethics and legal professionals and other interested stakeholders outnumbered its relations with the lay public. For example, Richard Doerflinger of the National Catholic Conference of Bishops had the privilege to speak before Council members a total of six times between January 2002 and December 2004. The Council held about 17 'public' meetings, but not many scholars were on hand to discuss the issues. Most scholars and scientists were invited to present their research and views on stem cell research in the form of seminar

presentations, which allowed a range of practical aspects of stem cell policy such as philosophical views of human nature to be discussed.¹⁵ However, the discussions that emanated from these presentations were often closed to the general public.

Critics have also argued that the debate remained within the conservative perspective. However, while the Council's membership certainly includes more conservatives than had served in earlier panels, some claim that it is unfair to call the Council stacked.¹⁶ According to the former chair Leon Kass, there is much heterogeneity in the intellectual capacity of its members, and that any accusations that characterize the Council as a hyper-politicized group of right wing fundamentalists are false.^{17,18} The variety of backgrounds shows that there is indeed representation of a range of perspectives within the Council, but multidisciplinary does not automatically suggest that a diversity of issues are represented.

For example, public opinion surveys on stem cell research show that after 2001, the percentage of American citizens favouring medical research that uses stem cells from human embryos rose to 47 per cent from 35 per cent in 2004.¹⁹ At the same time, opposition declined from 51 per cent to 36 per cent in 2004, and strong opposition declined from 29 per cent to 22 per cent.²⁰ These statistics show that the general public was slowly favouring the use of new embryonic stem cell lines for research, revealing that the debate was not at the public level but at the expert and policy levels where the conservatives and religious right were debating the status of the human embryo with those who believed and continue to believe in a more liberal interpretation of the status of human embryos.

This kind of disagreement created a rift among Council members. Cynthia Cohen reports that the PCBE has had much difficulty maintaining an analytical framework for examining stem cell research. On the one hand, the Council tried to take a reasonable stance on stem cell research by using an approach that understands what it means to be human. However, some Council members had difficulty embracing a common understanding of human good in relation to embryo research.²¹ The Council also sought to engage in deliberation by using a moral consensus approach in the attempt to bridge differences within the Council, but this approach revealed to be just as difficult. Evidence of the disparate views is portrayed in the report *Monitoring Stem Cell Research* where the Council balances the pros and cons to restricting to the use of human embryos for research. Eventually the debates were bogged down by continual disagreement according to Blackburn. The Council later produced *Monitoring Stem Cell Research* with a proposal for a four year moratorium, which disheartened many of the Council's own members including Blackburn.²²

On the other hand, Francis Fukuyama recounts a slightly different experience that portrays the Council as equality driven. According to Fukuyama, Kass, the former chairman, went out of its way to take account of the many views. He states, "There was always remarkable diversity of opinion among the Council members, [and] in my personal experience, the Council's chairman, Leo Kass, and his staff were unfailingly even handed in their treatment of Council members."²³ The Council's transcripts however reveal a great deal of dissenting opinions mostly between the scientists and ethicists, and there is also evidence that some members, who worked in the same field, disagreed with each other. The lack of internal agreement had detrimental affects on the Council. On

more than one occasion the Council had to deal with internal conflicts, and less than impressive responses to their reports. This eventually led to the disputed dismissal of several members including Elizabeth Blackburn and William May. Other members including Francis Fukuyama did not renew their appointment with the Council.

5.3 Discussion

There is much evidence that points to the lack of a national debate on stem cell research. The PCBE's failure to embrace the diversity of American opinions is evident by the Council's process of deliberation and outcomes (i.e. reports and recommendations). The stark contrast between the Council's take on the stem cell research debate and how American citizens view the potential of stem cells is remarkable. For example, there is no doubt that a majority of American citizens show strong support for science and research. The percentage of Americans who believe that embryonic stem cell research is morally acceptable increased from 52 per cent in 2002 to 60 per cent in 2005.²⁴ While religious beliefs played a major role in this debate, 77 per cent of Americans who participated in this 2004 study claimed that religion was not important to them compared with 38 per cent of those who said that religion provides a great deal of guidance for them.²⁵

Interestingly, the political climate in the U.S. at this time did not reflect the same numbers. It was reported that most republicans, who at the time held the majority in Congress and the Senate, felt that allowing stem cell research and the destruction of human embryonic stem cell lines to continue was immoral. Even with the lack of consensus and ongoing debate amongst members, much of this sentiment is reflected in the PCBE's internal discussions and final reports (see *Monitoring Stem Cell Research*).

The PCBE itself was put together with an array of American experts personally chosen by President Bush (see table in appendix for more details about the PBCE). Furthermore, then chairman, Leon Kass, was particularly close to President Bush and also recognized as a conservative.²⁶ This suggests that politics had a lot of influence within the PCBE.

In addition to this, public deliberation was hindered by the technique used by the PCBE. In the first instance, there is no evidence that shows the Council sought public feedback after the publication of any of its reports. Secondly, all of the Council's meetings were held in Washington DC leaving perhaps many individuals with an important viewpoint outside the reach of the Council. Accessibility is an important feature of public deliberation. It is clear from the Council's transcripts that the majority of speakers were stakeholders with the means to present themselves before the Council.

Having said this, there was no real public deliberation effort in place by the Council while it considered the stem cell research issue. Although, the American public is generally informed about stem cell research, there is no real evidence that suggests the Council had a big role to play in the distribution of this knowledge. What is evident though is the fact that the Council engaged in a form of public consultation and not public deliberation while trying to understand the lay perspective on stem cells research. In general, the Council's rationale for this activity was not to collaborate with the general public as put forth by deliberative theory, but to solely consult with the public.

5.4 The Canadian Biotechnology Advisory Committee and Public Deliberation on the Ethical, Legal, Social and Moral Issues Surrounding Stem Cell Research in Canada

At the very early stages of the stem cell research debate, little was known about what kind of impact this research would have on Canadians. CBAC was the first national expert committee to examine the issues in early 2001. CBAC was established by the Canadian Biotechnology Strategy (CBS); a Canadian federal program to promote and encourage research and development throughout Canada. CBAC's mandate is to monitor, evaluate and seek public views upon rapid developments in the biotechnology industry. To grasp the extent of the stem cell research debate, CBAC in collaboration with the CIHR, also a federal research granting body in Canada, proceeded to canvass the spectrum of views across Canada by making public a consultation document on stem cells for citizen and stakeholder viewing. The goal of this activity was to grasp how Canadians felt about allowing research on human embryos to carry on in light of the ethical issues surrounding the usage of human embryonic stem cells in scientific research.

The following discussion examines the relationship between CBAC and public deliberation on stem cell research in Canada. The issues that have emerged from preliminary discussions in an earlier chapter are that CBAC did not have a formal method of engaging Canadians in debate. This is related to the fact that the stem cell debate in Canada emerged from a scientific perspective. More specifically, to set the standards for the public funding of research using human embryonic stem cell lines. Through a process that involved a multitude of steps, CBAC in collaboration with the CIHR put forth a document for public consultation that initiated a debate among Canadian stakeholders.

However, prior to the consultation document, CBAC did not have much information for the general public to access on stem cell research. What was available for public viewing was the committee's initial work on stem cell research, which was in the form of a report that studied the ethical, legal and social issues and how governments worldwide are dealing with the potential implications of stem cell research. The information in this report was general but presented a scoping review of the policy options for Canada. The significance of the report showed that CBAC needed to expand its knowledge on the subject and created an internal Project Steering Committee on stem cells and other emerging biotechnologies. This Project Steering Committee headed by Timothy Caulfield²⁷ explored the policy implications of the use of novel genetically based interventions such as therapeutic and reproductive cloning, stem cells, gene therapy and xenotransplantation.

At the same time, an independent expert panel was created to work at arms length with the government of Canada. This expert panel, chaired by William Leiss, was to produce reports on the issues relating to stem cell research. The products of this panel would also be considered input for CBAC and its Project Steering Committee. The intent of these committees was to take the information and engage in a dialogue with the general public.

With the help of the CIHR, this goal came to fruition through a consultation document titled *Human Stem Cell Research: Opportunities for Health and Ethical Perspectives*, which raised a debate on several important topics including the creation of a national oversight agency to monitor stem cell research across the country. The consultation document itself is short and easy for readers to comprehend the issues being

addressed. For example, the document starts with a general explanation of what stem cells are and gradually expands to a discussion on the issues arising from the use of human embryonic stem cell lines in research settings. It also explains the regulatory frameworks that currently exist worldwide and examines each to determine which legal framework could potentially be useful for Canada.

The consultation document was made accessible to the general public via the CIHR's website. It was specifically posted on the ad hoc Working Group on Stem Cells web page, which did not make it visible, and which may have been the reason why so few citizens had responded. Therefore, the public had to be made aware of this opportunity, but the end result showed that the majority of the responses came from other stakeholders more specifically religious and patient advocacy groups such as the Evangelical Fellowship and the Canadian Alliance, who oppose stem cell research in general.

The information that was gathered from the consultation was then used by the ad hoc Working Group to produce a stakeholder report. This report was the focus of discussion at an expert roundtable meeting organised by CBAC. This meeting brought together many governmental agencies and experts from a range of research areas all with an interest in stem cell research. Much of the dialogue that emanated from the consultation document on stem cells was therefore initiated and subjugated by experts. The discussions that preceded and led to the recommendations and later the *Assisted Human Reproduction Act* did not involve the general public. Most of the recommendations were made under the pretences of expert advice while little information was shared or discussed with the general public. CBAC now holds a series of

deliberations involving experts and the lay public across the country to discuss issues of national concern. However, this exercise was never realized during the discussions on stem cell research, and is mostly now used for public deliberation on genetically modified food.

5.5 Discussion

What stands out in this case study is the fact that a majority of experts involved in the discussions on stem cell research sat on more than one committee including CBAC's Project Steering Committee and the CIHR's ad hoc Working Group. It is true that the research community in Canada is considerably smaller than in the U.S. however, this fact raises concerns about the conflict of interest and that one committee could serve to justify the acts and decisions of the other. In addition, then newly appointed President of the CIHR, Dr. Alan Bernstein, had a close relationship with the biotechnology industry. Not only was Dr. Bernstein President of the CIHR but he also chaired a consortium known as the Toronto Biotechnology Initiative, which aimed to create a downtown research park.²⁸

What is also interesting about the stem cell research debate in Canada is that the very same CIHR ad hoc Working Group came to the conclusion to allow Canadian scientists to derive stem cells from embryos left over from fertility treatments or fetal tissue obtained from elective abortions.²⁹ This decision unleashed much anticipated debate in the academic community. Many critics of the guidelines argue that the Working Group disregarding many ethical and legal principles in the evaluation of stem cell research. Some of these arguments claim that there will be severe legal repercussion in the industry that involve question such as do scientists need to obtain informed consent

from patients of IVF treatments? And should IVF patients be informed at the outset of the possibility that their frozen embryos could be used for future research?

Leigh Turner's investigation of the guidelines also raises the point that the Working Group did not consider the range of arguments of individuals and organisations opposed to pluripotent stem cell research involving stem cells derived from embryonic and fetal sources.³⁰ What is also disturbing about the release of the CIHR guidelines and CBAC's recommendation to government is that many Canadians were unsure about what stem cell research really entails and how it will affect them.³¹ While survey research reveals that many Canadians supported and continue to support stem cell research, public deliberation on this subject was very thin leaving many Canadians confused about an appropriate response. A poll taken in 2001 by Pollara asked 1,700 Canadians to rate their knowledge on stem cell research and other reproductive technologies. The results found that the average response was 4.8 on a scale of 10.³²

Public deliberation, as understood by deliberative theorists, between Canadians and experts was therefore reduced to a consultation exercise where the information on the subject was provided using the deficit model and not the deliberative model. The debate that did emanate from the discussion paper was framed from an expert perspective and disregarded much of what citizens and other stakeholders had to contribute to the debate. That being said, it is clear from this discussion that CBAC's initial intent was not to collaborate with the general public (see more about CBAC in table in appendix). While CBAC to a certain extent did inform Canadians about pluripotent stem cells, it fell short at fostering any type of public deliberation on stem cell research.

5.6 Conclusion: Comparing the Case Studies

The case studies above reveal a ‘thin’ relationship between national bioethics committees and public deliberation on stem cell research. From a general perspective, it is clear from this analysis that when the stem cell research debate emerged interest in public deliberation as defined by deliberative scholars was in its infancy. Additionally, the role of citizens in science policy was and continues to be a challenge. In the case studies, the PCBE and CBAC, although mandated to raise a national debate, failed to include the general public in a national debate on stem cell research for the following reasons.

Firstly, both institutions lacked what is known as a deliberative framework. A deliberative framework aims to raise public awareness, educate the public, stimulate debate, involve citizens in problem solving and build capacity for policy development by representing the views of various stakeholders, experts and citizens. Secondly, without a deliberative framework, both committees were unsuccessful at framing the issues in a manner that appeals to the general public. In the case of the PCBE, the analysis reveals that the debate was framed from a stakeholder and expert group perspective, and while many critics of the Council have been inclined to think that the religious right has influenced the Council’s work, this analysis reveals this belief to be untrue. In fact, liberal and scientific views were considered equally in the Council’s deliberations. This should be distinguished from the fact that President Bush had established a policy on stem cell research before the Council had commenced its research, which only reveals that the Council’s work on stem cells had very little influence on stem cell research policy in the United States.

In the case of CBAC, the debate on stem cells was also framed from an expert perspective. In fact, the size of the ELSI research community in Canada raised important questions about conflict of interest. Many Committee members were also CIHR members reviewing the very same questions with stakeholders and expert groups within Canada. Most of these discussions had mainly taken place at meetings organised by the CIHR and CBAC. Raising the issue of accessibility and how vital it is for public deliberation. These events excluded the Canadian public and left aside very significant discussions about the future of stem cell research in Canada.

Public deliberation is only now being recognized as an important component of the policy making process. At the same time, we are also recognizing that socio-ethical debates about genetic technologies are complex and often multifaceted, which can make deliberation about these issues difficult. Especially since opinions vary depending on personal, communal and religious values. Nowhere is this truer than with genetic technologies. National bioethics committees must gauge social concerns and start discourses about these issues in order to properly reflect, in a multidisciplinary way, upon the consequences of political action or inaction.

- ¹ President's Council on Bioethics, *Monitoring Stem Cell Research*, Washington DC, 2004, 5.
- ² Mary B. Mahowald, "The President's Council on Bioethics, 2002-2004," *Perspectives in Biology and Medicine* 48(2)(2005): 160.
- ³ Ibid.
- ⁴ Ibid.
- ⁵ Ibid.
- ⁶ Lisa H. Harris, "Ethics and Politics of Embryo and Stem Cell Research: Reinscribing the Abortion Debate," *Jacobs Institute of Women's Health* 10(3) (2000): 147.
- ⁷ President's Council on Bioethics (PCBE), *Human Cloning and Human Dignity: The Report of the President's Council on Bioethics* New York: Public Affairs, 2002, 153.
- ⁸ Canadian Institutes of Health Research (CIHR), *Human Stem Cell Research: Opportunities for Health and Ethical Perspectives*, Ottawa 1998 available at <http://www.cihr-irsc.gc.ca/cgi-bin/print-imprimer.pl>.
- ⁹ Ibid.
- ¹⁰ Françoise Baylis, "Human Embryonic Stem Cell Lines," The Ethics of Derivation" *J Obstet Gynecol Can* 24(2)(2002): 160; J Hoey, "The Environments of Stem Cells-Biology, Ethics and Policy" *CMAJ* 166(8) (2002): 1005; Canadian Institutes of Health Research (CIHR), *Updated Guidelines for Human Pluripotent Stem Cell Research*, Ottawa 2005 available at: <http://www.cihr-irsc.gc.ca/e/28216.html>.
- ¹¹ Timothy Caulfield, "Bill C-13 The Assisted Human Reproduction Act: Examining the Arguments Against A Regulatory Approach," *Health Law Review* 11(1)(2002): 20.
- ¹² When the Council published *Human Cloning and Human Dignity: An Ethical Inquiry* President Bush had already decided months earlier to oppose cloning and that the destruction of human embryos was immoral.
- ¹³ Leon R. Kass LR, "Reflection on Public Bioethics: A View from the Trenches," *Kennedy Institute of Ethics Journal* 15(3)(2005): 245.
- ¹⁴ Raja, Mishra, "President Bush Bioethics Panel Has Little Influence" *The Boston Globe* August 31, 2004 available at: http://www.boston.com/news/science/articles/2004/08/31/president_bushs_bioethics_panel_has_little_influence/.
- ¹⁵ Ibid.
- ¹⁶ Margaret Foster Riley, and Richard A. Merrill, "Regulating Reproductive Genetics: A Review of American Bioethics Commissions and Comparison to the British Human Fertilisation and Embryology Authority," *Science and Technology Law Review* 6 (2005):33.
- ¹⁷ Leon R. Kass (2005), 226.
- ¹⁸ Indeed, members of the Council through 2004 included Elizabeth Blackburn, professor of biochemistry and biophysics, Stephen Carter, professor of law, Rebecca Dresser, professor of law, Daniel Foster, Chairman of the Department of Internal Medicine at the University of Texas Southwestern School of Medicine, Francis Fukuyama, professor of political economy, Michael Gazzaniga, professor of cognitive neuroscience, Robert George, professor of jurisprudence, Mary Ann Glendon, professor of law, Alfonso Gomez-Lobo, professor of philosophy, William Hurlbut, professor of human biology, Charles Krauthammer, physician and syndicated columnist, William May, professor emeritus of ethics, Paul McHugh, Director of the Department of Psychiatry at John Hopkins, Gilbert Meilander, professor of Christian ethics, Janet Rowley, professor of molecular genetics and cell biology, Michael Sandel, professor of Government, and James Wilson, professor emeritus of management and public policy.¹⁸ New Council members include the new Chair Edmund Pellegrino, Floyd E. Bloom, and Benjamin S. Carson, whose backgrounds are all in medicine. Also included is Peter A. Lawler, professor of Government and international studies, and Diana J. Schaub, professor of political science.
- ¹⁹ Virginia Commonwealth University (VCU) Center for Public Policy, *Increasing Opposition to Cloning, but Greater Support for Embryonic Stem Cell Research*, VCU Life Sciences Survey 2004 available at: <http://www.vcu.edu/uns/Releases/2004/oct/VCU%20Life%20Sciences%20Survey-2004-Results.htm>.
- ²⁰ Ibid.
- ²¹ Cynthia B Cohen, "Promises and Perils of Public Deliberation: Contrasting Two National Bioethics Commissions on Embryonic Stem Cell Research," *Kennedy Institute of Ethics Journal* 15(3)(2005): 284.
- ²² Elizabeth Blackburn, "Thoughts of a Former Council Member," *Perspectives in Biology and Medicine* 48(2) (2005): 172-80.
- ²³ Francis Fukuyama, "Human Biomedicine and The Problem of Governance," *Perspectives in Biology and Medicine* 48(2) (2005): 199.

²⁴ Lydia Saad, "Americans OK with Using Embryos in Medical Research," *Gallup Poll News Service* April 21, 2005 available at: <http://www.gallup.com/poll/content/?ci=16486&pg=1> .

²⁵ Virginia Commonwealth University (VCU) Center for Public Policy (2004).

²⁶ Leon Kass was often interviewed by Nigel S. deCameron of Chicago Kent University, who is also a conservative and Bush supporter. In these interviews, Kass often expressed his positions and views on stem cell research. His comments were also often featured in *Religion and Ethics Newsweekly* available at <http://www.pbs.org/wnet/religionandethics/week520/kass.html> .

²⁷ Timothy Caulfield is the Research Director of the Health Law Institute at the University of Alberta. In 2002 he received a Canada Research Chair in Health Law and Policy. He is also a Professor in the Faculty of Law and the Faculty of Medicine and Dentistry. His research has focussed on two general areas: biotechnology, ethics and the law; and the legal implications of health care reform in Canada.

²⁸ Francesca Scala, "Scientists, Government, and Boundary Work" in *Critical Policy Studies* (eds) Michael Orsini and Miriam Smith, UBC Press, 2006, 225.

²⁹ Wayne Kondro, "Canadian Panel Aims for Middle Ground" *Science Magazine* 292 (5514)(2001): 31-33.

³⁰ Leigh Turner, "Policy-making and Moral Reasoning: Why the CIHR Guidelines on Pluripotent Stem Cell Research are Inadequate," *Policy Options* 2 (2002): 42.

³¹ Chris Cobb, "Most Canadians Want Cloning Ban, Research Controls: Poll Shows Strong Majority Wants Agency to Regulate Reproductive Technology" *The Ottawa Citizen* Jul 20, 2001, A1.

³² Ibid.

Chapter 6

The Future of Public Deliberation in North America

6.1 Introduction: Overview of Study

Today, policy experts face complex technologies that bring with them socio-ethical and legal implications. They are now finding that these issues are too multifarious to be dealt with without an appropriate evaluative framework and a political body to evaluate societal implications. At the same time, public awareness has grown and shown that policy experts are not always unbiased and omnipotent.¹ To contour these challenges, governments have turned to bioethics committees to survey new technologies, but to also appraise public opinion through citizen engagement. As presented earlier in this study, there are scholars such as Dzur and Levin, who believe that the latter is the primary responsibility of bioethics committees however there are many counterarguments to this view.

This study has investigated whether the PCBE and CBAC, two important institutions in North America, managed to foster a national debate on stem cell research by comparing them to an ideal model of a national bioethics committee drawn from relevant literature and theory. It is safe to say, at this juncture, that both institutions failed to raise a national dialogue. In the first instance, the PCBE's public deliberation initiative was hindered because of political influence, lack of institutional independence and the use of an ineffective public deliberation technique. CBAC, on the other hand, failed to foster a national debate because the issues were poorly framed, conflict of interest between committee members, lack of institutional independence, and like the PCBE, the use of an ineffective public deliberation technique. Having said this, the following

chapter explores in more detail the variables that have contributed to the failures of the PCBE and CBAC and closes this study with a view to the future of public deliberation and public bioethics in North America.

6.2 About Stem Cell Politics

While most of the public controversy in the United States and in Canada has focused on the issue of embryo use and destruction, other ethical and policy issues have attracted attention as well.² Examples of such questions include: should federal funds be allocated towards research that many consider unacceptable? What limits or restrictions should be placed? And what are the moral implications for not supporting potential life-saving technology?

For three decades, U.S. federal public funding of stem cell research has been banned. The lack of public funds for stem cell research is also prompting states to fill the void such as is the case in California and New Jersey, where stem cell research funding is available. While public funding has been brought to a halt, privately funded³ stem cell research has been able to thrive and grow exponentially. Who should regulate and what should be regulated are questions that have shadowed all progress in this area. There are many stakeholders with interests in this research area making it a crucial economical issue. Public interests have politicized this area as well.

When the PCBE was mandated to address these questions, there were doubts about whether the group would be able to maintain an unbiased opinion. With this concern in mind and supported by existing legislation (FACA and FOIA), the PCBE, led by its then chairman Leon Kass, made clear that it would keep a neutral stance and seek

out what all stakeholders believe would be the appropriate government action or inaction should be. The Council sought to bring the public back into the policymaking arena with honourable intentions. However, its connection to high level government offices, including the executive branch of the U.S. government, led to much speculation about its independence and ability to foster a neutral opinion. Some scholars however argue that the history of U.S. national advisory commissions shows this relationship to be normal as a commission established by the president should be linked to the president, but an ideal national bioethics committee, as discussed in chapter three, is a committee that is institutionally independent and free of political influences.

Given the situation, the Council could not distance itself from the politics of stem cell research. Much of what was being debated in the media and in political circles stemmed from the 1973 U.S. Supreme Court decision in *Roe v. Wade*. The decision that emerged from the litigations in this case was subsequently interpreted in many ways leaving room for debate about what to be done with discarded embryos. Not long after, the U.S. government responded to this debate by banning the use of federal funds for research on embryos, foetuses, and embryonic or foetal tissue.⁴ However, the issue had not been resolved for those who endorsed stem cell research.

Much of the Council's work was handicapped from the very beginning. It was composed of eighteen formally appointed members, personally selected by President Bush. Many of the members were sympathetic to the conservative view even though they came from various backgrounds including religion, ethics, metaphysics, moral philosophy, medicine, law, political theory, public policy, and biology. This led to concerns that the Council was unfairly stacked, forcing its chairman, Leon Kass to come

to its defence on several occasions.⁵ In fact, he once expressed proof of the Council's heterogeneity is found in the intellectual diversity of its members, and that any accusations that characterize the Council is a hyper-politicized group of right wing fundamentalists are false.⁶

However, former member Elizabeth Blackburn did not see it the same way. In an article, she claimed that politics weighed heavy on the Council and bogged down any potential the Council had at producing valuable work in this area. William May, although much less disdainful of the Council, accounts that Council meetings on stem cell research were often very coloured.⁷ From his account three answers emerged from the Council. Some scientists denied the link between the microscopic material in a Petri dish and "one of us" and therefore justify unregulated research.⁸ A second group-proponents of the ban-defined "one of us" to include the human embryo.⁹ The third perspective emerged from the view that the status of the human embryo is intermediate and it is therefore neither a full human nor a mere thing.¹⁰ With such divided views, the Council has been unable to come to an agreement about whether research using human embryos should be regulated or left unregulated.

Former Council member Francis Fukuyama also recounts that the Council went out of its way to take account of the many views. He states, "There was always remarkable diversity of opinion among the Council members, [and] in my personal experience, the Council's chairman, Leo Kass, and his staff were unfailingly even handed in their treatment of Council members."¹¹ However, transcripts of the Council meetings reveal that discussions were often skewed with usually two minority groups with dissenting views often scientists and ethicists, but there is also evidence that some

members, who worked in the same field, disagreed with each other. The alleged dismissal of members only fuelled scepticism about the ability of the Council to independently produce recommendations on the stem cell research issue.

In Canada, it was the 1993 Royal Commission on New Reproductive Technologies that first addressed embryo research. However, it was not until Canadian researchers began to ask what type of research could be publicly funded that Canadian policymakers realised there existed a policy void in this area. It was at this time that CBAC and the Canadian Institutes of Health Research (CIHR) began to address the issues.¹²

At this time, CBAC was composed of twenty-one volunteer members from various disciplines that rotated between sessions. The members were selected based on personal attributes and nominated through a public process that includes a review by the Biotechnology Deputy Minister Selection Panel. From this point, recommendations were made to the Biotechnology Ministerial Coordinating Committee, which then makes the final selection. The final composition of the committee is selected publicly providing citizens with an opportunity to participate in the selection of members. The pitfall of this selection process is the fact that the nomination process is performed directly by the Biotechnology Deputy Minister. In other words, CBAC answers directly to a government agency. CBAC itself is institutionally connected with the Canadian bureaucracy.

Additionally, the experts nominated to the committee were pooled from the Canadian researcher community. The consequence of this is that many of the same individuals participated on other high level committees including the CIHR committee mandated to examine the stem cell research issue and produce the consultation document

that was distributed to stakeholders. It is clear from this analysis that the CBAC case presents issues of independence and conflict of interest similar to that of the PCBE. This is particularly interesting since both national committees work in different governance systems- a presidential system and a parliamentary system, which suggests that these committees differ on a structural basis but are similar in many ways on issues of mandate and relations to government.

6.3 Public Deliberation Techniques

CBAC's work with public deliberation on the stem cell research question was also ineffective at garnering a national debate. The technique opted by CBAC and the CIHR was to consult stakeholders about the potential uses of human embryonic stem cells deemed acceptable. Many of the stakeholders that responded to the consultation document put out by the CIHR were aware of its existence and availability, while ordinary citizens were not. Therefore, the majority of respondents were interest groups. Ordinary citizens were unaware that they could provide their views and sentiments about what course of action the Canadian government should take.

Moreover, the debate elicited by the consultation document was primarily focused on the ethical implications of scientific mishaps by Canadian researchers. Other socially relevant issues were not discussed or mentioned. This has much to do with the fact that the framing of the issues were from an expert standpoint. This stands in stark contrast with what ideal public deliberation, as outlined in chapter two, specifically calls for. That is dialogue between all stakeholders and policymakers to create a reason-giving process

that is ongoing and open. Additionally, public deliberation must involve stakeholder education to ensure that discussions are framed in a neutral and general manner.

The examination of the PCBE also reveals that public commentary is an inefficient way to foster public deliberation for the following reasons. Firstly, public commentary did not bring together stakeholders and policymakers. It did, however, allow stakeholders to interject comments during the PCBE's semester meetings. Council members appraised stakeholder comments, but there was no opportunity for stakeholders and Council members to engage in dialogue. Moreover, there was little opportunity for stakeholders to engage with each other. Secondly, public commentary did not afford accessibility to all. Accessibility was granted to those who could pay for the costs associated with visiting Washington DC for Council meetings. Public commentary transcripts have showed that some stakeholders had multiple chances to speak before the Council, while other equally significant groups did not.

Ideal public deliberation is said to enhance liberal democracy in a way that citizens and authorities can talk about what is best for society as a whole. Deliberation not only provides citizens with an opportunity for enlightenment but also offers citizens a chance to rebuild a connection with their government and with other citizens. It also elicits decision making on that basis.¹³ Moreover, a successful public deliberation effort has the following features: (a) a realistic expectation of influence (i.e. link to decision makers); (b) an inclusive, representative process that brings key stakeholders and publics together; (c) informed, substantive, and conscientious discussions; and (d) a neutral, professional staff that helps participants work through a fair agenda.¹⁴ Having said this,

it is safe to conclude that the techniques used by the PCBE and CBAC to raise a national debate on stem cell research were inefficient and ineffective.

6.4 Conclusion: The Future of Public Deliberation and Public Bioethics

Public bioethics has an enormous future ahead particularly since advancements in genetic technologies are progressing at a rapid rate. Governments need experienced experts to evaluate the appropriate courses of action needed to address the complex socio-ethical issues raised by these new technologies. However, this does not suggest in any way that ordinary citizens do not have a place in science policymaking. If anything, this thesis has shown that there is ample room for the ‘scientific citizen’ and the ordinary layperson.

Public deliberation techniques are being ameliorated everyday, and new ways are emerging which enable citizens to reconnect with the policy arena. ‘Bringing the public back in’ is a work in progress and was a process, as we know now with little doubt, a major challenge for national bioethics committees in North America at the turn of the twenty-first century. What can be said about the future of public deliberation and national bioethics committees is that they both have the potential to reconcile social, moral and ethical differences, teach ordinary citizens about science, and reconnect people with democracy.

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- ¹ Sato Hajime, and Akira Akabayashi, "Bioethical Policymaking for Advanced Medical Technologies: Institutional Characteristics and Citizen Participation in Eight OECD Countries," *Review of Policy Research* 22(4) (2005): 583.
- ² President's Council on Bioethics (PCBE), *Monitoring Stem Cell Research*, Washington DC, 2004, 5.
- ³ What is meant by privately funded research is research financed by corporations and foundations.
- ⁴ Dorothy C. Wertz, "Embryo and Stem Cell Research in the United States: History and Politics," *Gene Therapy*: 9(11)(2002): 674-678; JC Fletcher, "Deliberating Incrementally on Human Pluripotent Stem Cell Research," in *Ethical Issues in Human Stem Cell Research Vol. II Commissioned Papers* National Bioethics Advisory Commission, US Government Printing Office: Rockville MD, 2000, E1-E50.
- ⁵ Margaret Foster Riley and Richard A. Merrill, "Regulating Reproductive Genetics: A Review of American Bioethics Commissions and Comparison to the British Human Fertilisation and Embryology Authority," *Science and Technology Law Review* 6 (2005): 33.
- ⁶ Leon R. Kass, "Reflection on Public Bioethics: A View from the Trenches," *Kennedy Institute of Ethics Journal* 15(3)(2005): 226.
- ⁷ William F. May, "The President's Council on Bioethics: My Take on Some of Its Deliberations," *Perspectives in Biology and Medicine* 48(2) (2005): 234.
- ⁸ Ibid.
- ⁹ Ibid.
- ¹⁰ Ibid.
- ¹¹ Francis Fukuyama, "Human Biomedicine and The Problem of Governance," *Perspectives in Biology and Medicine* 48(2)(2005): 199.
- ¹² Canadian Institutes of Health Research (CIHR), *Human Stem Cell Research: Opportunities for Health and Ethical Perspectives*, Ottawa 1998 available at <http://www.cihr-irsc.gc.ca/cgi-bin/print-imprimer.pl>.
- ¹³ Phillip Pettit, "Depoliticizing Democracy," *Ratio Juris* 17(1)(2004): Abstract.
- ¹⁴ Peter Levine, et al., "Future Directions for Public Deliberation," *Journal of Public Deliberation* 1(1)(2005): 1-13.

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Appendix A

| Characteristics | Relation to Public Policy | Goals of Public Involvement | Potential Variables that Can Hinder Ideal Public Deliberation |
|--|--|---|--|
| <ul style="list-style-type: none"> • Provides citizens with new information through public awareness and the exchange of knowledge. • Participant focussed: allowing citizens consolidate and develop co-membership in a collective form of life by way of public reasoning with other citizens who owe their identities to the same values and traditions. • Gives citizens an opportunity to identify shared ideas through reciprocity and concerns and assign priority to issues of national concern. • Can be on a large scale or small scale (e.g. consensus conference, citizen forums) including experts, policy makers and other stakeholders. • Involves reciprocal respect among reasoned equals. Is open, universal and provides fair access to political institutions. • Outcomes are just and fair. • Does not yield a consensus because, ideal public deliberation is open-ended. | <ul style="list-style-type: none"> • Positivist vs. Post-positivists: the challenge to applying lessons and procedures of the natural sciences to social settings by trying to extract and codify universal laws and their responding behaviours. • The policy science of democracy as introduced by Laswell who speaks of a need for the policy sciences to 'democratize society'. In other words, the strengthening of democracy and its values by involving the views of those affected by proposed policies • Branch of the policy sciences that builds upon a more democratic approach to public policy. • Frank Fischer talks about participatory policy analysis and criticizes conventional models of experts and scientific expertise.¹⁹ Need more of a collaborative mode of policy making. • Science policy has emerged as an area saturated by experts and technocrats as described by Schneider and Ingram. • Sheila Jasanoff argues that traditional modes of policy making involving the monopolization of information of experts are waning. Science and technology are evolving at a rapid pace and with it are citizen movements that have become deeply involved in science policy seeking a more 'open government' approach to policy making. | <ul style="list-style-type: none"> • Facilitate public discussion on issues of national concern. • Involve demographically representative groups of citizens in the policy making process. • Raise awareness and educate the public on issues of national concern. | <ul style="list-style-type: none"> • Realities of daily life. • Administrative systems and processes. • Participation techniques. |

Public Deliberation

| Characteristics (Who they are and What they do) | Goals of Public Involvement (Why engage?) | Public Deliberation Modus Operandi | Tools for Public Involvement | Potential Variables that Can Hinder Ideal Public Deliberation |
|---|--|--|---|---|
| <ul style="list-style-type: none"> Corporate group created by a public act on an <i>ad hoc</i> or <i>permanent</i> basis. Reports and other documents (e.g. staff papers) are also for public scrutiny and ensuring transparency (usually enforced by public act e.g. FACA and FOIA). Members are drawn from outside government circles to ensure independence and non-partisanship. Members are usually prestigious expert representative of major interests. Members are usually selected on the basis of expertise because of the "issues to be considered involve technical matters (medical, legal, social, or philosophical ones". Members serve as both as technical experts and as representatives of the broader moral community mandated to "advise", "study", "recommend", "gather information" or something similar. Respect the basic principles of a liberal democracy (e.g. justice and freedom) in the analysis of issues. Encourage public dialogues by specifying who shall be heard, when, where and how. Develop guidelines and recommendations for government. | <ul style="list-style-type: none"> Receive high level support by the public on issues of national importance. Produce recommendation s/guidelines to government based on information that clearly highlights the public's shared priorities. | <ul style="list-style-type: none"> Identify a social issue. Establish deliberation procedures (e.g. when, how and who will be invited to deliberate) at the outset by members of the committee. For example, the U.S. Human Embryo Research Panel was under mandate in terms of form of deliberation, and the manner in which they would choose to relate their deliberations to public processes, societal views, and members vigorously negotiated consensus at the outset. An example of a deliberation procedure: The PCBE decided that public engagement would be in the form of public commentary. Gather facts, hear from concerned parties, consider the wisdom of relevant extant policies, respect civil rights and moral agency of those involved, and entertain reasonable appeals". Frame issues in a neutral and comprehensible manner. Educate the public through concept articulation and public awareness.⁹ Provide the public with access to information on the issue being deliberated. Obtain feedback from the public on the issue being deliberated. Synthesize the arguments in a formal report to government. | <ul style="list-style-type: none"> Deliberative polling Consensus conferences National issues forum Online deliberative polling Focus groups Citizen Juries | <ul style="list-style-type: none"> Restriction of access to public dialogues (e.g. majority of participants being from interest and stakeholder groups). Debate framed in a manner that excludes the general public. Political and ideological influences. Conflict of interest of Committee members. |

National Bioethics Committees

| Characteristics (Who they are and What they do) | Goals of Public Involvement (Why engage?) | Public Deliberation Modus Operandi | Tools for Public Involvement | Potential Variables that Can Hinder Public Deliberation |
|---|--|--|--|---|
| <p>The President's Council on Bioethics (PCBE)</p> <ul style="list-style-type: none"> The PCBE was created by Executive Order 13237 in 2001. It was created on an ad hoc basis (in the US national advisory committees are created with a termination date which usually coincides with the ending of the president's term). It is usually composed of eighteen formally appointed members that are personally selected by president in office. All members of the PCBE come from various backgrounds not exclusive to religion, ethics, metaphysics, moral philosophy, medicine, law, political theory, public policy, and biology. A chairman is chosen by the President to lead the Council. (Former chairman Leon Kass and present chairman Edmund D. Pellegrino. | <ul style="list-style-type: none"> Undertake fundamental inquiry into the human and moral significance of developments in biomedical and behavioural science and technology. Explore specific ethical and policy questions related to these developments. Provide a forum for a national discussion of bioethical issues. Facilitate a greater understanding of bioethical issues. Explore possibilities for useful international collaboration on bioethical issues. Respect the Freedom of Information Act (FOIA) and the Federal Advisory Committee Act (FACA). | <ul style="list-style-type: none"> Identify an issue that is of national importance. After identifying the issue, the PCBE researches and scans the various points of views. It prepares a document for consultation (e.g. Monitoring Stem Cell Research (2004). Prepares for a Council meeting in Washington DC. Invites a select group of expert speakers to present research papers addressing the issues under study by the Council. At the end of each meeting the Council hosts a public commentary session where the Council is sensitised to a range of public views. The process of public commentary is speaker oriented and there is no dialogue between Council members and speakers. | <ul style="list-style-type: none"> Public commentary. | <ul style="list-style-type: none"> Restriction of access to public dialogues (e.g. majority of participants being from interest and stakeholder groups). Debate framed in a manner that excludes the general public. Political and ideological influences. Conflict of interest of Committee members. |

| Characteristics (Who they are and What they do) | Goals of Public Involvement (Why engage?) | Public Deliberation Modus Operandi | Tools for Public Involvement | Potential Variables that Can Hinder Ideal Public Deliberation |
|---|--|--|---|---|
| <p>Canadian Biotechnology Advisory Committee (CBAC)</p> <ul style="list-style-type: none"> • The Canadian Biotechnology Strategy established CBAC. • It is a committee with permanent status within the Canadian bureaucracy. • It is composed of twenty-one volunteer members from various disciplines that rotate between sessions, and that serve on the Committee for 3 years. • The members are selected based on personal attributes and are nominated through a public process that includes a review by the Biotechnology Deputy Minister Selection Panel. <p>From this point, recommendations are made to the Biotechnology Ministerial Coordinating Committee, which then makes the final selection.</p> | <ul style="list-style-type: none"> • Receive high level support by the public on issues of national importance. • Produce recommendations/guidelines to government based on information that clearly highlights the public's shared priorities. • Build public confidence in biotechnologies. | <ul style="list-style-type: none"> • The first phase involves the identification of an issue of national importance. • CBAC requests a review of the current situation by commissioning an outside expert to prepare a report for the Committee. • CBAC members are separated into working groups where they collect data and prepare synthesized reports on the issues whether they are ELSI in nature or research related issues. • The data collected is used to build a consultation document. (in the stem cell case, the consultation document was prepared in collaboration with the Canadian Institutes of Health Research (CIHR)). • The consultation document was posted electronically on the CIHR website. • CBAC seeks to validate the issues and options, impacts and effects, and to identify "values" that must be addressed in formulating advice. • The consultation document is also released to the stakeholder and expert communities. • The second phase is then completed with the release of an interim report containing draft recommendations. • The final phase involves the composition of a final report with final recommendations that takes into account all of the input received. | <ul style="list-style-type: none"> • Public consultation (consultation document) | <ul style="list-style-type: none"> • Restriction of access to public dialogues (e.g. majority of participants being from interest and stakeholder groups). • Debate framed in a manner that excludes the general public. • Political and ideological influences. • Conflict of interest of Committee members. |