

Stem Cell Research, Publics' and Stakeholder Views

Robin Downey and Rose Geransar

Introduction

Stem cell research (SCR) is an important new area of biomedical research that offers promising therapeutic possibilities for a wide range of diseases and injuries. However, it is also a research domain filled with many players and fraught with ethical, legal and social issues, posing significant challenges to policy makers. From regulators who make decisions about how scientists can (or cannot) carry out their work, to patient organizations with vested interests in therapeutic promises, from opponents of the research, to interested publics, SCR has managed to intrigue, provoke, promise and dismay.

As a controversial technology, SCR has provoked sustained public interest. It is not surprising that stem cell policy has been attentive to what policy makers perceive as the views of publics and stakeholders. In this paper, we explore how different publics have responded to SCR. We also examine the roles and impacts of interested stakeholder groups, including patient groups, organizations opposed to certain forms of SCR and scientific research organizations. These stakeholder groups express their viewpoints in various arenas including the media, official committees, parliamentary arenas and research networks. We differentiate between different national contexts, and where possible, different segments of publics.

Public perceptions of SCR vary widely, reflecting controversies such as the varying perceptions of the origin of the cells. Stem cells can be derived from adult tissues and organs, including the umbilical cord blood (UCB) or bone

marrow (adult stem cells, or ASCs); aborted fetal tissue (fetal stem cells); or human embryos (embryonic stem cells, or ESCs). Although embryonic stem cells are often touted for their pluripotent properties, there is scientific evidence that stem cells from some non-embryonic sources also have pluripotent-like properties.¹ The future of stem cell therapy is thought to depend in large part upon matching specific sources of stem cells to the diseases for which they are the most suitable as a treatment.² This empirically-driven 'source / disease match' framework within the scientific community is in stark contrast to the normative political discourse that dichotomizes the stem cell debate between "adult" versus "embryonic" stem cell sources.

Another part of the debate around SCR has centered on the use of human embryos in research. Human embryos can be obtained from in-vitro fertilization (IVF) clinics that have excess embryos in storage (with consent from the donors), or through a process called somatic cell nuclear transfer (SCNT), the basic technique of cloning, in which the nucleus of an adult cell is transferred to an enucleated egg. The process of cloning embryos for research is often referred to as "therapeutic cloning", despite the fact that no clinically proven ESC-based therapies exist as of yet.³

The complexity of discourses around SCR therefore presents challenges for policy makers and publics, resulting in uncertainty. Providing opportunities for broader engagement and participation in SCR research could enhance knowledge, transparency and participation among public stakeholders.



1. Attitudes of Publics and Beneficiaries of Stem Cell Research

Ulrich Beck's influential *Risk Society* argues that a key characteristic of today's social and political landscape is that publics have become more critical regarding scientific and technological issues.⁴ Moral risks related to SCR include concerns about the status of the embryo, in addition to other less tangible concerns related to the transgression of moral boundaries, as illustrated dramatically by the cloning debate.⁵ In the media, the cloning controversy has often been represented through metaphors, e.g., comparing biotechnology to *Frankenstein* or *Boys from Brazil*, thus emphasizing dystopic views of the new technology.⁶ SCR has also been associated with the same set of concerns that emerged around cloning, especially in the light of events surrounding Dolly the cloned sheep. Arguments from the abortion debate also resurface around stem cells, because of the use of embryos in some forms of SCR. Conversely, the promise of SCR holds broad appeal for proponents, in both the public sphere and in the medical and scientific community.

This section begins by discussing general public opinion in jurisdictions where SCR has been particularly controversial, including Canada, the US, the European Union (EU) and Australia. Patients' perspectives are also examined. Publics' perceptions of SCR in different countries and regions may be discussed in terms of levels of familiarity with SCR, perceptions of different sources of stem cells and stability of public opinions over time. In countries in which SCR is discussed in the context of highly polarized moral debates, factors such as the reported levels of "religiosity" of publics become a key explanatory variable. Trends within the EU as a whole are offered with the caveat that they represent average values of poll results from countries with very different social and political contexts surrounding SCR. Also, the notion of "publics" is treated as distinct from other "stakeholders," the latter term referring to individuals whose collective actions are guided by or directly serve the mandate of an overarching organizational framework.

a. SCR Awareness

Public awareness of SCR has been highest in Canada and the US, and is not strongly correlated with public support. Greater familiarity with SCR among Americans (83%), compared to Canadians (68%),⁷ however, may well be rooted in media coverage and representations, rather than in informed understanding of the science involved. In the US,

SCR has been a high profile issue in the media, in part due to the advocacy efforts of celebrities such as Christopher Reeve, Michael J. Fox and Nancy Reagan. Media characterizations of SCR in cartoons – which have painted positive and negative pictures of the potential impact of SCR in the US – may also be considered "easy access points" for engagement of publics in the stem cell debate.⁸ Reported awareness of SCR may therefore represent awareness and acceptance of the competing frames through which media presents the SCR debate, as opposed to awareness of the relevant scientific and policy issues.⁹

In countries that are part of the EU, one in ten people on average admit to being "very" or "fairly familiar" with SCR. Familiarity is highest in Denmark (61%), Italy (48%) and the U.K. (45%), and lowest in some new member States such as Estonia (12%), Latvia (10%) and Lithuania (9%), as well as in Greece (9%). In the EU, there seems to be stronger correlation between awareness and support than in the US.¹⁰ However, the extent of public awareness of SCR in the EU is not associated with the intensity of the public debate in individual countries, as might be expected. For example, in Germany, only 20% of respondents reported familiarity with SCR, despite intense public debate.¹¹ Finally, in Australia, while one-third report being familiar enough with SCR to "explain it to a friend", the majority indicated that they know little or nothing about the topic.¹²

b. Perception of Benefits and Risks of SCR

In Canada, the US and Australia, perceptions of benefits associated with SCR are far greater than perceptions of risks. The vast majority of respondents in all three countries anticipate that SCR "will improve their way of life" in the future.¹³ In both Canada and the US, approximately nine out of ten people perceive "moderate" to "substantial" benefits from SCR.¹⁴ In Australia, the same proportion of people consider stem cells "useful" for conducting medical research and for treating disease.¹⁵ No systematic comparison is available on perceptions of benefits and risks across European countries. However, when survey respondents from EU Member States were offered categorical choices regarding what kind of information they want regarding SCR,¹⁶ sixty percent expressed interest in information about the potential benefits and risks.¹⁷

Perceptions of risks associated with SCR are generally low, but are higher in Canada and the US than in Australia. A majority in both Canada and the US perceive "moderate" to "no risks" in SCR (79% and 77%, respectively). However



in Australia, over half of respondents consider “no risk”¹⁸ ensuing from SCR,¹⁹ compared to only one quarter in the US, and one fifth in Canada.²⁰ Perceptions of risk have been found to be the main drivers of the degree of regulatory stringency preferred by publics in Canada and the US.²¹ For example, those who perceive moderate to high risks from SCR are also more likely to prefer that SCR be more tightly regulated than those who perceive little or no risks. In Canada and the US, however, perceptions of risks have not been found to have bearing on whether or not an individual will express overall support for SCR. Instead, perceptions of moral issues have been found to be the strongest determinants of individual support for SCR.²²

Due to the value-laden nature of the term “risk,” it is important for all opinion-measurement tools to define the kind of risk being discussed in order to convey the most meaningful results. For example, surveys ought to differentiate between risks to embryos, donors and society. Unfortunately, not all surveys recognized this nuance. This distinction is particularly important in light of research showing that different concerns are expressed about SCR depending on the source of stem cells. Canadian focus groups show that the primary concern about ASCs is viability, and umbilical cord blood stem cells raise questions of informed consent and commercialization. ESC research raises primarily moral questions, and SCNT consistently conjured fears of misuse of the technology.²³

c. Support for SCR

The majority of people in Canada, the US, the EU and Australia approve of SCR, though public opinion regarding SCR is extremely variable among EU Member States. A cross-Atlantic study comparing Canada, US, and the EU has shown that Canada has the highest total approval, with eighty percent of people approving of SCR with current or tighter regulations; followed by the US, with more than seventy percent;²⁴ and then the EU with almost sixty percent of people reporting approval.²⁵ An independent survey in Australia has shown that eighty percent of people in that country also approve of SCR for “medical” and “research” purposes.²⁶

When publics are divided into segments based on principles of technological decision making, four categories emerge: 1) scientific elitists, who opt for decisions taken on expert advice based on scientific evidence; 2) scientific populists, who opt for decisions based on average citizen’s views of the scientific evidence; 3) moral elitists, who opt for decisions taken on expert advice based on moral and ethical criteria; and 4) moral populists, who opt for decisions based

on average citizen’s views of the moral and ethical issues.²⁷ Within these groupings, scientific elitists²⁸ (or “technocrats”) are more likely to approve of SCR with the least constraints, while moral populists are more likely to reject SCR. These contrasts are more pronounced for Canada and the US than in Europe.²⁹ These categorizations are the result of an assumptive analytical framework being imposed upon a set of data in order to discern patterns in public attitudes towards science policy.

Approval of SCR is often contingent upon different policy conditions, which are in turn driven by perceptions of risk. Figure 1 shows a summary of SCR approval rates in Canada, the US and the EU under different policy conditions. In the US, the majority of supporters of SCR approve under the “usual levels of government control.” In both the Canada and the EU (overall), the majority of supporters would approve under tighter regulations, though the EU survey asks specifically about “embryonic stem cells.” Trends across the EU vary widely. In Netherlands and Denmark, for example, a large percentage of supporters (41% and 36%, respectively) also approve of ESC research with current levels of regulation.³⁰ European Union countries with the highest levels of net disapproval of ESC research (over one third) also reported comparable levels of “don’t know” responses.

Confidence in the regulatory system has been found to be higher in Canada than the US. When asked to rate their confidence in the “safety and regulatory approval systems governing stem cell research,” over three quarters of Canadians reported being “confident” or “moderately confident.” Canadians also show more trust in scientists engaged in SCR, with over two fifths reporting that they are “confident” that “stem cell research is in safe hands.”³¹ Europeans reported that they tend to trust the EU more than their national governments, but a systematic cross-comparison of the EU Member States is not currently available regarding the degree of public trust in the national regulatory systems.³²

d. Support of Different Stem Cell Sources

Support for SCR is strongly dependent upon the source of stem cells, and this contingency is stronger in Canada and the US than in Europe. Considering support for different sources of stem cells can help pry apart important distinctions made by publics in different national contexts. The sources of stem cells most often enquired about in surveys are: ASCs, including UCB, and ESCs. Stem cells derived from human embryos have been the most controversial.



Figure 1. Contingency of approval of SCR on policy conditions in Canada, US and the EU¹

	Total approval	Approve with usual levels of government control	Approve if more tightly regulated	Do not approve except under exceptional circumstances	Do not approve under any circumstance	Total disapproval	Don't Know
Canada ⁱⁱ	81	36	45	14	4	18	4
US ⁱⁱ	73	41	32	19	3	21	9
EU ⁱⁱⁱ	59	23	36	17	9	26	15
Belgium	73	13	60	16	7	23	5
Sweden	73	25	47	17	4	21	7
Denmark	69	41	28	20	4	24	7
Netherlands	67	36	31	23	4	27	7
Italy	66	15	51	12	4	16	17
Spain	63	29	34	10	7	17	19
France	62	19	43	16	8	24	14
U.K.	62	28	34	15	6	21	17
Luxembourg	59	20	39	23	9	32	9
Germany	54	32	22	22	16	38	8
Greece	52	12	40	27	20	47	2
Finland	49	24	25	34	9	43	9
Austria	45	20	25	25	15	40	15
Portugal	45	18	27	18	4	22	33
Ireland	36	15	21	19	11	30	34

¹ Data based on a question that was phrased as follows: (In the European Survey) “Overall, which of the following best captures your view about research using embryonic stem cells?” In the North American Survey, the question was: “Overall, which of the following best captures your view about stem cell research?” The four options specified in the middle white columns were provided.

ⁱⁱ See note 7.

ⁱⁱⁱ See note 10. Data for the old European Union Member States are shown in the table to show the range of public approval ratings of SCR among EU Member States; new Members States as of May 1, 2004, are excluded.³³



The majority of individuals in all regions report support for ESC research, with the condition that it is tightly regulated. Approximately sixty percent of persons surveyed in Canada, the EU and Australia approve of ESC research, whereas a little over fifty percent of Americans surveyed report such approval.³⁴ However, other surveys report greater support cutting across political, religious and socioeconomic demarcations among Americans (66%).³⁵ Reported support for ESC research in the UK has ranged from 57%³⁶ to 70%,³⁷ and as high as almost 75%.³⁸

The highest approval rates for ESC research are found in Belgium, Sweden and Denmark, with approximately seventy percent of ten people approving of ESC research. The lowest levels of support were found in Ireland (36%) and some of the new EU Member States also reported low awareness of SCR.³⁹

Support for ESC research is highly contingent upon the purpose for which the embryos that are used to derive ESCs are produced. Public opinion is much more favorable towards the use of ESCs that are derived from excess IVF embryos originally intended for reproduction, rather than embryos created through SCNT (cloning) and originally intended for research or therapy.⁴⁰ In US surveys, the majority of people, ranging from sixty to seventy-five percent, report opposition to the creation of embryos for research purposes,⁴¹ but a similar majority is accepting of the use of excess IVF embryos for research.⁴² In Canada, however, there is support for both the use of excess IVF embryos (94%) and cloned embryos (58%) for research, despite the fact that the latter practice is banned.⁴³

In Canada, the US, the EU and Australia, all surveys report higher levels of support for ASC research than for ESC research. In the European Union, about two thirds (65%) support ASC (specifically, UCB stem cell) research. Support for ASC research is the highest in Canada and the US, with almost ninety percent of individuals supporting the use of stem cells derived from “adult” sources.⁴⁴ For EU Member States, the difference in levels of support for ASC and ESC sources are small. For example, in Italy, Spain, Sweden and Hungary, approximately eighty percent of individuals approve of both ESC research and ASC research.⁴⁵ In the UK and Australia, support levels are also high, at eighty and

seventy-five percent of respondents, respectively.⁴⁶ Again, the lowest levels of approval are observed in some of the new EU Member States, such as Slovenia (40%), Estonia (47%) and Latvia (52%), where awareness and support of SCR are low in general.⁴⁷

Public perceptions of the use of UCB stem cells in Europe may be complicated by the application of pre-implantation genetic diagnosis due to the high-profile issue of “saviour siblings.” The process involves selectively choosing an embryo whose cell markers will match that of an existing ill sibling, so that the UCB of the resulting baby will be suitable for treatment of that sibling.⁴⁸ Experts have noted that the practice is on the rise, and public opinion studies show support for embryo selection for UCB donation.⁴⁹ Close to seventy percent of individuals would approve of producing saviour siblings, including 11% who would approve only “under exceptional circumstances.”⁵⁰

Religiosity (measured as frequency of church-going per week) has been found to be positively associated with disapproval of SCR in both the US and Europe.

e. Religion & Value Frameworks

In Canada, survey results have indicated that moral issues are determining factors in whether publics support or oppose the development of SCR.⁵¹ In the United States, research has revealed a tendency of publics to allow personal values and existing ideological frameworks to guide their opinions on issues pertaining to SCR.⁵² While some surveys have reported that the extent of personal religious practice and ideological conservativeness in the US is associated with disapproval of SCR,⁵³ other surveys have shown that “Fundamentalist and Evangelical Christians” in the US are split evenly on approval for ESC research.⁵⁴ This trend is more evident in Europe, where countries with predominantly traditional Protestant and Catholic religions have the highest levels of public approval of ESC research. The fact that most Europeans surveyed consider the embryo to be a human being after conception is not a decisive factor in public approval of ESC research; the majority of Europeans in EU countries will approve of the use of ESCs so long as tight regulations are in place. However, religiosity (measured as frequency of church-going per week) has been found to be positively associated with disapproval of SCR in both the US and Europe.⁵⁵



f. Stability of Public Opinion over Time

Public support for SCR has increased over the past two years in both the US and Australia.⁵⁶ Overall, public opinion has been responsive to media coverage of recent events. In the US, for example, public opinion survey results on SCR tend to fluctuate, with the results being contingent on current events, the context of the survey and the manner in which issues of creation of embryos for research and therapeutic purposes is presented.⁵⁷ Two “neutrally worded” American polls that have tracked public approval of ESC research consistently show that approval gradually rose after 2001, then slightly decreased after 2005.⁵⁸ Other survey results have been inconsistent due to biases introduced through the wording of the surveys or contextualization of the questions. Survey terminology (e.g., “somatic cell nuclear transfer” versus “cloning”) and the extent to which potential harms and benefits are described (e.g., as offering cures for diseases versus killing of embryos) tend to be reliable predictors of survey results.

Many surveys have found that the majority of Americans (58 to 75%) support research on stem cells derived from excess IVF embryos.⁵⁹ However, a Gallup Poll that inquired about the use of embryos created solely for research purposes found only 38% support.⁶⁰ When it was specified that embryos were created using SCNT, public approval increased to 72%.⁶¹ The largest US public opinion poll avoided use of the term “stem cell” and any discussion of the benefits and risks of SCR and found that only 24% of the public approved of the creation of embryos for research purposes, with approval being higher in men, people under the age of 50 and individuals with no religious affiliations.⁶²

Media responsiveness to current events has played an important role in the instability of the results of public opinion polls in the US over time.⁶³ When media attention to SCR increases and wider public attention is attracted, it is often under conditions where the main focus is the morality debate and political conflict, rather than the science or policy issues.⁶⁴ In general, events such as the involvement (and death) of high-profile advocacy figures in the stem cell debate,⁶⁵ have received increased media coverage in Canada, the US and Australia, thus shaping the stem cell debate.⁶⁶ In the US, such events have been found to have an important influence on the results of public opinion polls.⁶⁷ Key events in one country can also permeate borders; for example, during the US presidential elections, media coverage in the UK portrayed SCR as an area where the UK could get a “jump-start” in economic growth relative to the US.⁶⁸

g. Patient Perceptions

Patients constitute a special group of potential beneficiaries of SCR, whose individual voices face obscurity by being counted as a segment of publics or marginalization under the broad banner of various patient lobby groups. There is little academic literature discussing individual patient’s perspectives on the conduct of SCR and the challenges that arise from it. What is known about the attitudes of these direct and potentially immediate beneficiaries of SCR is mostly gathered from online dialogues generated by patient advocates, patients’ involvement with resource websites and their attendance at both scientific and patient-centered conferences.

The European Commission and the European Federation of Neurological Associations recently funded a conference in Belgium to bring together patients and patient representatives from 34 European countries to engage in discussion with scientists, physicians, religious and political representatives as well as the media about the issues and challenges relating to SCR and its therapeutic applications.⁶⁹ A poll taken at the conference showed that 91% of a hundred voting patients were in support of ESC research. These patients pointed out that many people who voice concerns about SCR are not themselves “in a state of need”; they urged the EU not to allow abstract ethical debate to prevent funding of research that may alleviate the suffering of patients and their families. Nevertheless, there was a consensus about the importance of “reaching out” to those who opposed research “in order that a debate may move forward in an open and transparent manner.”⁷⁰

Patients have also actively pursued other independent means of influencing the stem cell debate. American physician and quadriplegic Claude Gerstle, and his daughter, a former producer at NBC, recently attended the International Society for Stem Cell Research’s 4th annual conference in Toronto, Canada, as part of preparation for a documentary on stem cells from a “non-advocacy” standpoint.⁷¹ Regarding his interest in SCR, Dr. Gerstle said:

After my injury a number of friends asked if I was looking into research with stem cells being done in Israel and elsewhere. After reviewing the literature I felt it was probably more hype than hope, that many people had very little knowledge of what stem cells are, where they come from and what they might be useful for. We want to educate the general population as to the nature of stem cells especially since they



will need to make informed choices in the current debate over the use of leftover embryos and future debates over therapeutic cloning.⁷²

Patients often express attitudes and share experiences regarding stem cell therapy using both ASCs and ESCs through general or disease-specific online forums, or other forms of media. For example, the UK-based Multiple Sclerosis Resource Centre provides links to patients' accounts of their experiences with stem cell therapies using UCB, autologous bone marrow and ESCs. Regarding her success with UCB stem cell therapy in Rotterdam, one UK patient wrote: "I don't know the science behind my miracle cure—and I don't care."⁷³ For many such patients, therapies offered within the auspices of other legal jurisdictions are considered the only alternative to experiencing the deterioration of their health as a result of their illness. Another MS patient who observed positive results after traveling to Barbados for ESC treatment from IVF derived embryos wrote: "It's just so aggravating that the politics get involved. Let the doctors do what they are supposed to do and heal us."⁷⁴ These attitudes may be a trend among patients suffering from illnesses and conditions that tend to steadily and significantly worsen over time.

Other patients urge caution regarding unproven treatments using stem cells from all sources, but especially with regard to ESC clinical trials offered in countries with loose stem cell regulations.⁷⁵ Quadriplegic patient Jean Swenson of Minnesota takes a more cynical attitude regarding ESC-based therapies. She writes: "some who want the approval and funding for basic ESC research offer misleading promises about nonexistent ESC cures." Swenson emphasizes that financial resources should be focused on ASC treatments that "already have shown they will work."⁷⁶ Similar criticisms have been put forth in Australia, demonstrating the extent to which advocacy roles in SCR become internationalized. For example, an Australian doctor and patient criticized Christopher Reeve's ESC research advocacy efforts, insisting that money should instead be invested to facilitate access and care for people with disabilities.⁷⁷ Reeves responded by saying that there need not be any conflict between care and cure; both can and should be supported.⁷⁸

Public debate has also been generated through citizen forums. The Consensus Conference has emerged as a means through which governments may engage and educate their citizens on controversial topics such as SCR. The process typically involves a variety of experts with diverse positions, in an attempt to give the lay public an opportunity to become well versed on different aspects of an issue. In Norway, for example, members of the public have been allowed the opportunity to deliberate on stem cells as lay panelists. A Consensus Conference in Norway provided an opportunity for informed discussion and input from the

public. In this case, the Consensus Conference was considered quite successful, as noted by Ole Borge, a senior advisor for the Norwegian Biotechnology Advisory Board:

I would like to say a few words about the Consensus Conference we held in Norway on the topic of stem cells. It was a great success . . . The Norwegian conference triggered a debate that had been latent for two years . . . It

was a great experience for Norway, and I suggest that other countries could do the same.⁷⁹

The panelists opted for a moderate position toward SCR, supporting research on excess embryos but prohibiting the creation of such embryos specifically for research. Pamphlets, produced after the conference, are still being reproduced and disseminated to schools.⁸⁰

The majority of publics in Canada, the US, Europe and Australia support ESC research when it is tightly regulated, and public support is almost unanimous for ASC research. Publics tend to have greater familiarity with SCR in North America than Europe. Data shows that the assumption that greater familiarity leads to greater support is misguided; ideological and religious values tend to temper public support for SCR in the United States, and to a lesser extent in Europe. Public awareness, knowledge and support of SCR are susceptible to influence by media coverage and key political and social developments, which are in large part influenced by various stakeholder groups. In the following section, we will review the positions of these groups and their activities.

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2. Stakeholder Views and Activities

Stakeholders have played a major role in the stem cell debate, and, in turn, in the research and policy developments in this area, affecting the ways in which scientists can do their work. Stakeholders are those organized groups in society directly involved with, or strongly affected by the developments in question. Among stakeholders, patient groups in alignment with the medical community are the most visible drivers of SCR. They are motivated by the promise of cures and treatments for diseases such as diabetes, Multiple Sclerosis and Parkinson's Disease. Other powerful forces for research are the academic and industry scientists working in the area. Groups and institutions opposed to SCR constitute another category of interest. The pro-life position, which generally opposes ESC research and any form of research that uses embryos, has been relatively successful in Canada, although not as influential as in other national contexts. These stakeholders have become involved in policy developments through a variety of strategies, including networking, contributions to policy forums, mobilization of supporters and raising the awareness of the general public.

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a. Stakeholders, Policy Arenas and Committees

Three policy positions on SCR represent markers for sites of contention and agreement. The first is what we call the narrow approach, allowing research on a limited set of cell lines but prohibiting research on human embryos. The US federal policy position exemplifies this approach. The second allows research on excess IVF embryos, as illustrated by the Canadian policy and reflected in a number of EU states. The third is the least prohibitive position, which allows for the creation of embryos for the purpose of producing stem cells, as demonstrated by UK policy. It is the source of stem cells that is at the center of social contestation and policy debate.

These policy positions raise a variety of ethical concerns, from issues of human dignity to commodification of life,

in addition to the more basic question of when life is said to begin. At the same time, these concerns are countered by views that emphasize SCR's medical potential. Some see ethical concerns that are formulated in a vague manner as a hindrance to SCR policy development. For example, one commentator notes that "the ambiguity that surrounds the concept of human dignity makes its value as a regulatory tool relatively limited."⁸¹ However, these ethical concerns

have been at the core of policy debates in many countries, including Canada, the US and Australia.⁸² Others insist that ethics and morality must remain paramount.⁸³ These views are difficult to reconcile and are taken into account to varying degrees in different policy contexts. The various debates underline the complexity of taking ethical considerations into account in policymaking.

In the UK, despite broad public support and a liberal approach to SCR that allows therapeutic cloning under tight regulations, to an extent some public concerns are still ignored by policy makers.⁸⁴ The UK position is also one that has provoked concern among other EU countries.⁸⁵ Approximately one fifth of survey respondents report general disapproval of SCR, and close to one fifth remain undecided (Figure 1) — a much larger undecided proportion than in Canada or the US. This discrepancy raises questions about the range of stakeholders that are taken into account by policy makers, leading to the conclusion that "public skepticism has prompted little change in the constitution of these policy networks or their technocratic conclusion."⁸⁶ The polarized nature of the debate surrounding stem cells has been a hindrance for some stakeholder communities.

The EU has taken a more cautious approach to SCR, attempting to reconcile different national policy environments within the context of a larger political framework, in part because of difficulties in arriving at a unified policy position.⁸⁷ The EU will finance SCR within the existing policy frameworks of the host countries if the projects do not involve human cloning, human gene modification or the "destruction" of human embryos, including for the purpose of deriving stem cells. This means that the EU will continue funding research on adult stem cells and existing human



embryonic stem cell lines.⁸⁸ This position has caused some tension with the more liberal British support for SCR.⁸⁹

One arena within which various views can be aired is the public hearing where stakeholder groups and expert communities can present their positions. Stakeholder committees provide another forum to examine policy questions, allowing various stakeholders to play roles in the debate. These types of committees and organizations may not directly support specific positions regarding SCR, and so are not necessarily strategic by nature. This distinguishes them from the networks of support outlined in the section below.

Three early committees were very influential and concluded that some research on human embryos was acceptable: the Warnock Committee in the UK (1984); the Canadian Royal Commission on Reproductive Technologies (1993); and the NIH Human Embryo Research Panel in the US (1994).⁹⁰ The US National Bioethics Advisory Commission (NBAC) was another influential stakeholder committee. The NBAC was mainly used by the Clinton Government to explore issues of cloning, which involves similar techniques. This commission likely affected the development of SCR in the US: “NBAC may have strengthened arguments in support of stem cell research, making it politically impossible for President Bush to prohibit stem cell research altogether, two years later.”⁹¹ Support for SCR may well have been stronger specifically because of the inclusion of specific stakeholders: “The Commission’s accountability to science was also arguably reinforced by the commissioners’ strong identification with academic culture (11 were university professors or administrators), and their reliance on scientific expertise to inform their deliberations.”⁹² In contrast, and reflecting the politics of SCR, the subsequent President Bush’s Council on Bioethics focused more deliberately on the moral dimension.

Stakeholders are also effective through presentations in policy arenas, which have the potential to affect policy quite directly. For example, in Canada, the Standing Committee on Health heard presentations by a broad spectrum of stakeholders, including religious and patient groups.⁹³ Although there was not political consensus among all stakeholders on the “moral status of the embryo,” the Canadian policy context was defined, in part, by the voices that were strongly opposed to research on embryos:

[T]he moral status of the embryo, at the political level, became the primary driver behind the Canadian policy debate. This leads to the

conclusion that Canadian policy on Somatic Cell Nuclear Transfer has been shaped by one constituency’s view of the moral status of the embryo.⁹⁴

The scientific research community in Canada felt the influence of the pro-life groups, examined in the section below. In Canada the embryos cannot legally be created for research, in either a private or public context.



Figure 2. A pin exemplary of rhetorical strategies used by Democrat supporters and SCR advocates (Evolve Fish website: (<http://www.evolvefish.com/fish/buttons-ss4.html#2246>))

In the United States, where the debate is the most polarized, at key moments—such as the last presidential election—support for SCR played out very publicly through positions staked out by politicians and in the media (Figure 1). For example, the election button in Figure 2 reflects the views of SCR supporters. Past research by Nisbet has found that increased “awareness” of SCR has not directly translated to increased support for SCR in the US because both religious and ideological values have strongly attenuated the impact of this information on public opinion.⁹⁵ However, this research has also found that American publics have tended to rely on information that is most readily available to them and their underlying values to develop opinions about SCR. These previous findings imply that the recent data showing increased support for ESC research in the US may be a result of increased media and political attention in recent years. However, this is an area where further research is warranted.

The more visible controversy in the United States centres on human ESC research.⁹⁶ Research varies significantly by state, and between public and private spheres. Scientists can use public funds to do ESC research on federally approved ESC lines, and private funds to do research on non-approved or newly derived ESC lines.⁹⁷ This results in an environment that is involved in controversial research and existing regulation has simply not caught up to these developments:

Currently most embryonic stem-cell work in the United States is done by private companies, using regulations not specifically designed for this type of research. In the absence of federal guidelines, the academies last year issued its own, and the committee is intended to keep these periodically updated.⁹⁸

The American case illustrates the potential for industry to become the main site of SCR research, with outcomes that are less visible to the public, policy makers and other stakeholders.

b. Networks of Hope and Support

Research alliances and other interest groups play a key role in garnering support for more open research. These are similar to “science advocacy movements,” e.g., The American Association for the Advancement of Science and the Coalition for the Advancement of Medical Research.⁹⁹ In the case of SCR, such groups are the primary venue in which scientists engage in policy outcomes. Networks of scientists researching stem cells also offer effective means of collaboration and support. Canada’s Stem Cell Network is the first of its kind and was followed by others, e.g. Scotland, California, England and Australia. These organizations function mainly as a means to support research and scientists. As noted by Castellani, “[s]cientists in the field agree that they need a single voice to speak to governments and put pressure on decision-makers for a common legislation. [Europe’s] new network . . . could provide such a voice.”¹⁰⁰ However, participation by ethicists is also an important factor.

Transnational networks are now developing: the European Stem Cell Network held their inaugural meeting in November 2004, and the Canadian Stem Cell Network is spearheading an attempt to establish an International Stem Cell Network. In addition, the International Society for Stem Cell Research (ISSCR) recently published a set of guidelines for conducting SCR, representing “the most comprehensive effort to date to compose a set of principles for the conduct of human ESC research that would pertain to research worldwide.”¹⁰¹

Other moves towards harmonizing research at the international level include a recent stakeholder meeting in support of ESC research in Hinxton, Cambridge. The Hinxton meeting generated a set of principles publicly articulated by a group of authoritative figures, which form a basis for further public and political dialogue. It is also a very signifi-

cant step toward scientific self-regulation. Where science is unregulated, there are often vast differences in scientific and ethical standards, and the quality of the research itself is called into question.¹⁰² This raises questions, for example, regarding a new Singapore research center called Biopolis, “a self enclosed science city, housing government research institutes, biotech start-ups and global drug companies,” which is attracting international researchers due to the freedom it offers for ESC research.¹⁰³

Scientists are the primary actors in stem cell networks, yet there is little systematic research regarding their responses to public concerns. Occasional expressions of personal viewpoints through communications and editorials in scientific journals suggest that many scientists are concerned about the degree of sensationalism and alarmism in the media coverage of SCR. They fear that in the absence of significant short-term clinical outcomes, these sorts of discussions will eventually undermine public trust in SCR.¹⁰⁴ A US mixed-method study, which compared biologists’, and consumers’ views on SCR, found discrepancies between each group’s main concerns.¹⁰⁵ While consumers’ concerns were mainly centred on religious issues such as “playing God”, the main concerns of biologists were regulatory and methodological, especially regarding controls and standards, e.g. sources of stem cells.¹⁰⁶

However, scientists hold a wide range of views on SCR. A UK study of scientific discourse on SCR found that researchers often set up different kinds of dichotomies regarding SCR, then shift among them in order to support their own niche within the field.¹⁰⁷ For example, a basic scientist may emphasize the utility of either ESCs or ASCs as a research tool, as opposed to a potential therapeutic intervention, thus setting up the field in such a way that it cannot fail to achieve the specified goal, namely, knowledge production.¹⁰⁸ Alternatively, the therapeutic goal may be projected on a timeline well into the future; scientists currently engaged in both UCB and ESC research insist that only by pursuing both ASC and ESC research can the long term goal of fully translating the basic science of stem cells to clinical therapies best be achieved.¹⁰⁹ Many scientists believe that therapeutic cloning will eventually prevail, and suggest that the current interest in ASC and ESC research is mainly oriented towards this end.¹¹⁰ Some scientists believe that ethical discussions can drive certain experiments, which then feed back into the ethical debate. An example of this is recent experiments showing that embryonic stem cells can be generated from cloned or normal embryos without destroying them.¹¹¹ Another example of ethics shaping the



path of scientific research is evident in the advent of Altered Nuclear Transfer, where the feasibility of an experiment devised by an ethicist is being tested in the laboratory in order to create an ethically neutral embryo-like entity to use in ESC research.¹¹²

Patient groups also play an important role, through research funding and policy support. For example, during the development of Canadian legislation, patient groups supported the Canadian Institutes of Health Research guidelines, in addition to pending legislation. Some patient groups engaged in several activities directed towards this end, including participating in the Standing Committee on Health and encouraging their members to write letters to Members of Parliament. Patient groups vary in terms of their position on stem cell development. The Juvenile Diabetes Foundation (JDRF), for example, is more likely to support therapeutic cloning than other groups. The Parkinson's Society, Muscular Dystrophy Association, and JDRF were more active in their campaigns and support than other groups, such as the Canadian Cancer Society. Although these groups were generally very supportive of policy developments which would allow embryo research, some patient groups may have been less outspoken about their support, having been swayed by the activities of pro-life support groups who would often send letters to supporters of ESC.¹¹³ This could influence patient organization funding of ESC research projects in the future.

Patient groups have achieved important public profiles and greater influence by working with public spokespersons and through partnerships with scientists and other stakeholders. The most visible movement leaders for patient groups have been Christopher Reeves, Michael J. Fox and Mary Tyler Moore. Patient groups have been very effective at partnering with scientists and industry around developments in SCR, and they are an important member and driver of networks of hope. They do this through funding research projects in addition to partnering with industry and other organizations. For example, JDRF funds a collaborative program called *EuroStemCell*, a virtual European stem cell center combining the expertise of over a hundred researchers across 27

research groups in 14 partner institutions.¹¹⁴ They have also partnered with the Wellcome Trust in a project focused on the development of stem cell lines and ESCs.¹¹⁵

In Canada, SCR has mainly been focused on ASC, with some attention being paid to broader research. For example, Dr. McIlroy, a representative of the Multiple Sclerosis (MS) Society of Canada, suggests that, despite their current focus on ASC, he can see ESC coming down the road.¹¹⁶ The Heart and Stroke Foundation is partnering with other organizations, including the Canadian Stem Cell Network and researchers, on the development of cardiovascular applica-

tions of stem cell therapies.¹¹⁷ Spokespersons for other groups, such as The Arthritis Society of Canada, express more ambivalence to SCR, but consider themselves hampered by supporters who are not in agreement with that research direction. Both a medical expert and the Executive Director of the Alberta branch of the Arthritis Society of Canada have emphasized this position.¹¹⁸ This is a dilemma not uncommon among other patient organizations.¹¹⁹

Religious groups have used a range of strategies to influence stem cell developments, including attempts to influence patient groups. For example, letters have been sent to patient organizations threatening to withdraw support if the organization supports SCR.

c. Religious Groups

Religious groups began to be politically active on SCR after the early committees, such as the Warnock Committee in the UK, had already developed positions on ESC research. While not all religious groups are opposed to SCR, many have become politically active around this issue. This is particularly true in the US where many religious coalitions such as Christian Coalition, the National Right to Life Committee and the Coalition of Americans for Research Ethics have mobilized against ESC research.¹²⁰ In Canada, Campaign Life Coalition was particularly instrumental in mounting a campaign around legislation for SCR.¹²¹

Religious groups have used a range of strategies to influence stem cell developments, including attempts to influence patient groups. For example, letters have been sent to patient organizations threatening to withdraw support if the organization supports SCR.¹²² Of course, such tactics do not always work — as shown by the position taken by the Michael J. Fox Foundation for Parkinson's Research.¹²³ However,



some groups may alter their position under the pressure of controversy. The National Multiple Sclerosis Society in New York and the Alzheimer's Association in Chicago "have not spent any money for embryonic stem-cell research, either because they do not believe it is a high priority, or because of the ethical controversy surrounding it."¹²⁴

Omerod found, after interviewing several members of the health charity sector, that there was a strong need for discussion within the sector on ethical issues surrounding new developments such as SCR. According to her, there is a "need to address our moral silence and be silent no longer. As leaders, both staff and volunteers, of national health organizations, we need to create the context and the structure for these ethical debates."¹²⁵

Religious groups can also influence the debate by promoting specific viewpoints regarding the scientific issues involved.¹²⁶ Although the scientific community's attention is fixed on human ESC research and therapeutic cloning, current focus on and developments in ASC research may well be attributed to the controversy surrounding research on embryos and fears of cloning. Recently, *Time* reported that "[s]cientists who are having surprising success with adult stem cells find their progress being used by activists to argue that embryo research is not just immoral but also unnecessary."¹²⁷ Some commentators suggest that the American "Christian Right" misrepresent scientific issues strategically, claiming, for example, "that abortion causes mental problems in women, that condoms aren't very effective in preventing HIV and other sexually transmitted diseases, that adult stem cells have more research promise than embryonic ones."¹²⁸ However, religious groups, including Catholic and Jewish groups, are not opposed to all stem cell developments and have often promoted the benefits of exploring ASC research.¹²⁹

Conclusions

Ongoing development of SCR has been hampered by a polarized debate. Public hopes are tempered by fears regarding potential abuse of stem cell technology. Support and well-informed awareness of SCR remains sensitive to media coverage and key politico-social events, particularly in the US, making public opinion dependent on arguably extraneous factors. Personal, ideological and religious values also affect public support for SCR in North America, and to a lesser extent in Europe. However, the majority of publics express strong but cautious support for SCR, con-

tingent upon the development of stricter policy and regulatory environments. In Europe, this trend in public opinion has been reflected in the EU's decision to continue support for SCR under strict guidelines, despite dissension among some Member States. In the US, the polarized and highly politicized nature of the debate has led to a presidential veto on a move to promote and expand federal funding for SCR. In Canada and Australia, debate has resulted in a "moderate" position that allows SCR using excess IVF embryos.

A common thread running through policy environments in Canada, the US, the EU and Australia is the presence of networks of hope and support comprised of scientists, patient groups, industry and interested policy makers. Stakeholders that do not fit this mold have contributed to this debate through committees where possible, and through campaigns to garner media attention and policy debate. In Norway, for example, a Consensus Conference in 2001 gave diverse stakeholders an opportunity to engage in dialogue with a lay panel, and consensus formed around a moderate position. It would be useful to conduct more of these processes, in the light of further research developments, particularly in countries where there is still a great deal of controversy over SCR. There is a need for innovative ways of engaging publics that can overcome the challenge of "value predispositions" associated with the use of more traditional modes of educational outreach in North America.¹³⁰ Such modes may involve popular culture and take advantage of science journalism to employ alternative frames that avoid over-politicization / polarization of issues.

Controversy over SCR is motivating the exploration of new research possibilities. For example, Altered Nuclear Transfer, which bypasses the creation of an embryo, could mitigate disagreement among various stakeholders, though it also has its critics.¹³¹ At the same time, increasing international collaboration among scientists seems correlated with a greater impetus towards currently controversial research. There is room for greater dialogue between voices of hope and voices of concern. In the meantime, policy outcomes continue to reflect the on-going struggles over public and stakeholder views about what "saving lives" ultimately means.

The public can play an important role in technological developments. Scholars debate the role of public participation in this arena, noting that "publics have been romanticized for their participatory instincts" and "ridiculed for their ignorance."¹³² An obvious means through which to consider the role of public participation is in managing the uncertain-



ty that arises when diverse stakeholders become concerned with both moral and scientific risk issues.¹³³ As technologies become more complex, fears emerge that the general public is unable to engage with or deliberate on more sophisticated technologies. However, developments in biotechnology, for example GM food and xenotransplantation, have incited interest and provided opportunities for more nuanced forms of public participation.¹³⁴ These forms include deliberative models, such as consensus conferences, and citizen juries, which could also be a very effective policy tool for SCR. These models may be particularly valuable as communication tools, providing opportunities for a range of experts to engage with the public on a more level playing field.¹³⁵ Of course, public participation is not a panacea for technological controversies. However, more open forms of consultation could provide a means of alleviating controversy, particularly in the case of morally divisive research endeavours such as SCR. It would seem to be especially important to engage public stakeholders, given that opposing stakeholders already play an important role in the governance of SCR.

Robin Downey is a PhD Candidate in Communication Studies, and Rose Geransar is a PhD Student in Community Health Sciences, both at the University of Calgary.

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