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Glass houses: The power of money in bioethics research

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GLASS HOUSES:

THE POWER OF MONEY IN BIOETHICS RESEARCH

JOCELYN DOWNIE

Abstract

In this paper I explore the power of money in bioethics research and ask whether, while casting stones regarding financial conflicts of interest in health research, bioethics researchers are in fact living in glass houses. I first review the need for money in bioethics research, the sources of money, and key features of the money (specifically, the amount of money involved and the fact that the money often is embedded, encumbered, and required to be matched). Next I explore a range of possible objectives for the money transfer. I then examine the effects of this transfer and raise some questions and concerns about the role of money in bioethics research. I close with some suggestions for possible responses to these questions and concerns—suggestions concerning what bioethics researchers as individuals and as a community could do to more positively and progressively harness the power of money in bioethics research.

Introduction

In recent years, many bioethicists have spent considerable time and ink doing what might (uncharitably) be characterized as “throwing stones” regarding financial conflicts of interest and health research. For example, bioethicists have been critical of drug companies sponsoring university research and universities commercializing their research (Downie and Herder 2007). They have painstakingly connected the dots—Olivieri, the University of Toronto, Apotex, . . . money (Downie, Baird, and Thompson 2002). Healy, Eli Lilly, . . . money (Healy 2002, 2003). Vioxx, Merck, . . . money (Topol 2004; Beller 2005). Gelsinger, the University of Pennsylvania, . . . money (Gelsinger and Shamoo 2008). These critiques have been important, and we should continue to critically reflect on the place and power of money in health research and health care. However, it is also important to step back, cast a critical eye on the power of money in bioethics research itself, and ask whether bioethics researchers are living in glass houses. In this paper, the very lens that has been focused on science and medical research is used to look at bioethics research and both direct, and indirect, conflicts of interest for bioethics researchers. I first review the need (real or perceived) for money in bioethics research, the sources of money, and some features of the money that are important for the subsequent analysis. Next, I explore a range of possible objectives for the transfer of money into bioethics research. I then examine the effects of this transfer and discuss some questions and concerns that I have about the role of money in bioethics research. In an effort to end on a constructive note, I close with some suggestions for possible responses to the questions and concerns—suggestions concerning what bioethics researchers, as individuals and as a community, could do to harness the power of money in bioethics research in more positive and progressive ways.

I use Canadian examples throughout this paper as it is the context within which I live and work and so it is what I know best. That said, the issues that I raise are relevant for many other countries, and I hope that bioethics researchers in these other countries will reflect on the Canadian experience as it relates to their own. Glass houses are not a uniquely Canadian phenomenon (Eckenwiler and Cohn 2007).

The need for money in bioethics research

Individual bioethics researchers, quite obviously, need income whether it be to supplement university or hospital salaries or as their sole means of support as independent contractors. They may also need money to support their re-

search, for example, to pay for research assistance, computer equipment and support, and travel to conferences. They may also need money to subsidize their other non-research bioethics activities—in particular, teaching and service.

Institutions in which bioethics research is conducted also need money to support their research missions. For bioethics research, this support most commonly takes the form of research infrastructure including office space, equipment, supplies, and support services for research staff. Institutions also need money to support their non-research activities (again teaching and service) and often use money derived from research activities to underwrite these non-research activities. It is also important to note here that bioethics research often takes place in institute or center structures. This creates a more direct institutional need for money because institutes and centers are often required to be more financially independent and self-sustaining than traditional university departments or faculties. Therefore, bioethics institutes and centers often must raise not only research funds but also operating funds (including their own faculty salaries).

The sources of funding for bioethics research

Where attention has been paid to money and conflicts of interest in bioethics, it has typically focused on funding flowing from industry for contract research, consulting services, and advisory board membership (Sharp et al. 2008; Elliott 2005; Turner 2004). Various industries have been examined, including the pharmaceutical, biotechnology, and insurance industries, as well as the venture capital sector. However, there are numerous other sources of money in bioethics research that deserve attention. We must also look hard at research funding agencies (e.g., the Canadian Institutes of Health Research, the Canadian Foundation for Innovation),¹ government departments (e.g., Health Canada and Industry Canada), and arms-length (flow through) *sui generis* entities such as the Stem Cell Network (SCN) and Genome Canada.²

The metaphor of the iceberg is relevant here. The most visible part of the iceberg, the connections between researchers and funders that are easy to find, are largely not-for-profit entities: universities, hospitals, funding councils, advisory committees, and health charities.³ Delve deeper and you find government: Health Canada, Industry Canada, the federal Department of Justice, and provincial departments of health and economic development and trade. Delve still deeper and you find industry: Roche, Scion, Esso, BioEnvelop, Merck Frosst, Schering, Glaxo-SmithKline, Bayer, Pfizer, and Sun Life Financial Canada. All of these entities have provided money for bioethics research or researchers in Canada.

The iceberg metaphor applies here to the various sources of funding and their relative (in)visibility on researchers' curriculum vitae, websites, PowerPoint disclosure slides, survey responses, and journal articles—how much of the funding are we actually seeing or even able to see? The metaphor applies also to the effects of money on bioethics research and the concerns about these effects that will be discussed later in this paper—are we steering straight for something that has the potential to sink our enterprise?

Some features of funding for bioethics research

The features of research funding that are most relevant for the analysis that follows are the large amounts of money involved, as well as the fact that the money is often embedded, encumbered, and required to be matched.

Large amounts of money for bioethics research

The amounts of money awarded for bioethics research can be very large in both absolute and relative terms. Consider the following data from the websites of various national funding organizations:

- Total approved budgets for Genome Canada genomics and ethical, environmental, economic, legal, and social issues (GE³LS) (2001–10)—\$33,589,484 (average per grant \$3,732,164) (Genome Canada a)
- Total Stem Cell Network on Public Policy and Ethical, Legal, and Social Issues (ELS) (2001–7)—\$2,179,022 (average per grant \$77,822)⁴
- Total Canadian Institutes of Health Research (CIHR) on ethics research (1999–2009)—\$6,519,738 (average per grant \$123,014)⁵
- Total Social Sciences and Humanities Research Council (SSHRC) on bioethics (1998–2008)—\$838,745 (average per grant \$22,668)⁶

Embedded nature of bioethics research

Not only are the amounts awarded for bioethics research frequently large, but the projects are also frequently embedded within large-scale science projects. That is, the bioethics projects are an integral part of the applications submitted for the large-scale science projects and then continue to operate within the large infrastructure. There is a financial (inter)dependence. For example, the Stem Cell Network submitted one large application for funding through the Network of Centres of Excellence Canada program. The embedded nature of the bioethics

research is reflected well in the description of the “Strategic Program IV” on the SCN website:

Past (1st cycle) research was conducted in two fundamental ways. First, SCN established a program of basic research aimed at creating an integrated and interdisciplinary analysis of those ethical, legal and social issues (ELSI) in both Canadian and international contexts. Second, *ELSI researchers were integrated into many of the projects funded under Programs 1, 2 & 3, where ELSI support and guidance was warranted.*

Current (2nd cycle) research is focused on projects that are of interest to policymakers and to an ELSI core facility. *The ELSI core facility liaises with Strategic Programs 1 & 2 projects to identify emerging ELSI issues, to map out an expected timeline to the clinic and potential legal/ethical barriers that will arise. Guided by the SCN’s Clinical Trials committee, the facility prioritizes where the Network can have the most impact in easing the ethics/regulatory/policy pathways and undertakes or co-ordinates work to address the hurdles.*

...

The clinical focus of Programs I & II is supported and enabled by the research undertaken as part of Programs III & IV. Strategic Program III addresses the need for novel tools, reagents and devices, and is comprised both of independent projects as well as components integrated into projects from across the research portfolio. *Strategic Program IV [public policy and ethical, legal, and social issues] combines a research program that examines the wider public policy issues arising from stem cell technology with a core facility that will provide direct advice and support to clinical projects.* (Stem Cell Network; emphasis added)

Similarly, Genome Canada was set up to embed what it called genomics and ethical, environmental, economic, legal, and social issues (GE³LS) within the large science project infrastructure. Genome Canada “was given a mandate by the Government of Canada to develop and implement a national strategy for supporting large-scale genomics and proteomics research projects, for the benefit of all Canadians.” (Genome Canada b) In turn, regional Genome centres were set up across the country to engage in large-scale genomics research. Each Genome centre had to submit an application for funding and had to include a GE³LS component in their application. Each centre was required to set up a GE³LS program and each large-scale project was required to “include a plan to address those GE³LS aspects directly raised by the research” (Genome Canada b).

The phenomenon of embedding bioethics research within science projects is also manifest in a large number of CIHR grants and initiatives funded by other entities.⁷

The encumbered nature of bioethics research funding

The funds for bioethics research are also frequently encumbered. That is, they come with strings attached—goals in addition to the performance of the research. For example, many funders of bioethics research have an explicit commercialization mandate or mission. *The Canadian Institutes of Health Research Act* states that:

4. The objective of the CIHR is to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system, by
...
(i) encouraging innovation, facilitating the commercialization of health research in Canada and promoting economic development through health research in Canada.⁸

Genome Canada's commercialization mandate can be inferred from the evaluation plan for March 2009, which is based on the objectives outlined in the funding agreement with Industry Canada:

- The evaluation will measure overall performance in achieving the objectives identified in the Funding Agreement. The evaluation will include a review of the following:
...
(d) commercialization and corporate development. (Genome Canada b).

The Stem Cell Network's mission is "To be a catalyst for enabling translation of stem cell research into clinical applications, *commercial products* and public policy" (Stem Cell Network).

Bioethics research funds coming from these sources thus may come with a heavy commercialization encumbrance.

Matching requirements for bioethics research funding

Finally, granting entities sometimes require that the funds they provide be matched by funds from other sources. For example, for Genome Canada, "[T]he agreement with the Government of Canada stipulates that Genome Canada will raise the other 50 per cent of funding from other sources" (Genome Canada b).

Similarly, the CIHR Innovation and Industry programs are designed to help the academic community “interact with Canadian companies with an interest in health research and development. The programs promote a wide variety of peer-reviewed research and training projects *jointly funded* by Canadian companies and CIHR” (Canadian Institutes of Health Research; emphasis added). CIHR funds are matched 1:1 or 1:2 by industry within these programs.

Objectives of funding bioethics research

There are, of course, many admirable objectives for the funding of bioethics research: to advance knowledge and knowledge transfer, to increase ethical research and practice, and to increase ethical policy development. However, there are also other, less savory, possible objectives, including to:

- Co-opt—“to neutralize or win over through assimilation”
- Restrict—“to keep or confine within limits”
- Use—“to seek or achieve an end by means of”
- Shape—“to give a particular form to, . . . to cause to conform to a particular form or pattern, . . . to adapt to a particular use or purpose, . . . to direct the course of”
- Harness—“to bring under control and direct the force of.”⁹

With these sources, features, and objectives in the background, I turn now to the possible effects of money on bioethics research.

Possible effects of money on bioethics research

Money has several potential positive effects on bioethics research. It creates jobs for bioethics researchers. It provides financial rewards for bioethics researchers. It provides funds for research but also, indirectly, for education, policy development, and service in bioethics. It might also lead to bioethics research being of greater relevance; if people are willing to pay for it, the argument goes, we might reasonably assume that it has greater relevance to them. This could apply to direct consumers such as industry (e.g., commissioning papers on topics that directly affect it), as well as indirect consumers such as the public through national funding agencies (e.g., setting strategic themes for targeted research and directing money to those themes that are thought to be in the public interest).

Such effects are certainly attractive. However, there are also a number of significant negative effects that are possible. Money can have a negative effect

on what we do, what we don't do, what we say (and how we are heard), and what we don't say. Consider each in turn.¹⁰

What we do

Shifting to empirical research

When embedded in large scale science projects, the budgets for bioethics research projects are often required to be very large. To be in the game, budgets run in the hundreds of thousands rather than tens of thousands of dollars. Yet non-empirical bioethics research tends not to cost that much. Empirical research drives the costs up and so puts bioethics research in the budgetary ballpark of the embedded projects. If the research questions demand empirical research, then the inclusion of empirical work is justifiable. However, if the inclusion of empirical research is driven by a need to ramp up the budget, then serious questions should be asked.

Adopting the lab model

Another effect of embedding is the adoption of the lab model for personnel and a consequential increase in the student and research associate involvement (often as authors, whether acknowledged as such or not) and a consequent shift in the kind of research that can be done. The lab model is frequently adopted by embedded bioethics research for two reasons: first, it ramps up the budget; second, a lab model is the cultural norm in much of science, so the expenditures are recognized as legitimate by the science collaborators and in the peer review of the budget justifications. However, when you adopt the lab model, you see the involvement of a large number of junior researchers, fewer in the middle ranks, and very few senior researchers. The level of research capacity is different at the different levels of seniority, and yet there are not the same levels of work/divisions of labor possible in non-empirical bioethics research as there are in science research. As a gross oversimplification, first take a neuropsychology research project on the acquisition of second languages. It takes the senior professor to design the study, but it also takes a lab full of students to run the participants through the functional Magnetic Resonance Imaging (fMRI) tests. Now take a philosophy research project on a relational approach to the concept of personal identity. The conceptual analysis cannot be broken down into component parts that a group of undergraduate or graduate philosophy students can do following the design of the study by the senior philosophy professor. Embracing the lab model (in part, encouraged or necessitated by the budget issue discussed above) changes the kind of bioethics research done; for example,

the research tends to be more empirical and less conceptual/theoretical. Of course there is value in empirical bioethics research. Consider, for example, the value of the meta-analysis that was done to demonstrate a positive results bias in industry-sponsored medical research (Bekelman, Yan, and Gross 2003; Lexchin et al. 2003). However, empirical work should not be allowed to crowd out conceptual and theoretical work.

Moving the ethics questions downstream

Still another effect of embedding is a shift with respect to the starting point for the analysis. Once embedded, researchers spend more time asking “How do we do X ethically?” and less time asking “Is it ethical to do X?” When the science partner is already trying to do X, it will not be seen as legitimate by the team for the bioethics partner to question doing X. And yet, the prior question must at least be permitted to be asked even if not asked. A related effect of embedding is that more time is spent on partner service—research into questions that the science partners would like to have answered in service to their research. For example, in embedded projects one might expect to see more research into developing consent forms for stem cell transfer research than into intergenerational justice issues flowing from personalized stem cell medicine. An example of this phenomenon can be found in the evolution of the Stem Cell Network. Indeed, in the latest round of funding, this tendency appears to have been taken to an extreme. There is now a “core facility that will provide direct advice and support to clinical projects”:

Current (2nd cycle) research is focused on research projects that are of interest for policymakers and to an ELSI core facility. The ELSI core facility liaises with Strategic Programs 1 & 2 projects to identify emerging ELSI issues, to map out an expected timeline to the clinic and potential legal/ethical barriers that will arise. *Guided by the SCN's Clinical Trials committee, the facility prioritizes where the Network can have the most impact in easing the ethics/regulatory/policy pathways and undertakes or co-ordinates work to address the hurdles.* (Stem Cell Network; emphasis added)

Shifting the publication venues

The sources and features of money in bioethics research have also led to bioethics researchers increasingly writing in styles and publishing in venues that arguably do not lend themselves to the advancement of bioethics scholarship.¹¹ Specifically, when embedded or looking to embed with the large science projects, quality is measured in numbers of peer-reviewed publications, impact factors of the journals where published, and other measures of quality established for sci-

ence research. This leads to an emphasis on peer-reviewed articles over invited articles and book chapters and to shorter articles written for science audiences in particular journals.¹² With this shift, the complexity of analysis can be lost, as can be high-level debate in the literature among bioethics research peers.

Embracing the role of entrepreneur

The need for and availability of money may also lead bioethics researchers to become entrepreneurs (e.g., forming spin-off companies). One example is GenomePolicy Inc. This private company, apparently¹³ spun out of the University of Toronto bioethics research context, offered a course called The Genome Policy Program, which was sponsored by GSK, Merck, Pfizer, and the Ontario Genomics Institute, but nonetheless cost participants \$5,350 for three days (not including accommodation). The course was delivered at the University of Toronto School of Management Executive Education facility, and the program directors were faculty members at the Joint Centre for Bioethics and the School of Management at the University of Toronto, but checks were to be payable to GenomePolicy Inc. The website for the Genome Policy Program is registered to the Director of Operations and Scientific Strategy at the McLaughlin-Rotman Centre for Global Health, Program on Life Sciences, Ethics and Policy at the University of Toronto.

Narrowing the bioethics research agenda

The sources and features of money in bioethics research outlined above have also led to a large relative and large absolute amount of work being done on a narrow range of issues (that is, relating to genetics, genomics, and stem cell research). The narrow range is illuminated by reference to the fact that 24 percent of all CIHR ELH ethics funding relates to genetics/genomics and that GE³LS funding is five times greater than all CIHR ELH ethics funding. The high volume is illuminated by reference to the totals spent on GE³LS (\$33,589,482) and SCN ELS (\$2,179,022).

What we don't do (enough)

As a result of the funding sources and features outlined earlier, bioethics researchers may not do enough of the following:

▀ *Research on vulnerable populations issues*—As has been demonstrated above, a great deal of bioethics research is done on genetics and genomics issues but far less is done on issues affecting vulnerable populations, such as access to abortion for rural women or aboriginal health law and policy. Where is the work by Canadian bioethics researchers on aboriginal people in Canada, unsafe drinking water in Africa, and human rights in China? (Turner 2007).

Conceptual or theoretical research—A great deal of bioethics research is done on such pragmatic and programmatic issues as consent to treatment or research, but much less is done on the conceptual analysis of such issues as identity, trust, and justice in the health context or such theoretical projects as developing relational theory.

Critical research—A great deal of bioethics research is compatible with (if not outright supportive of) commercialization. Less is done that is critical work, for example, on the ethics of the commercialization mandate of national funding agencies and the ethics of promoting genomics in developing countries. Another example of a gap in critical research is in the area of research on bioethics research. It would be valuable to have a textual analysis study on the impact that the various sources, amounts, and purposes of bioethics research funding have on the results of the research but to do this properly would require researchers with appropriate methodological expertise (at least some from outside bioethics), transparency from the bioethics research community, positive peer reviews from the bioethics research community (as this empirical research would require research funds), and a safe environment for such research (the protection of academic freedom for the researchers and a bioethics research community that does not penalize researchers for conducting such research).

Investigator-driven research—Topics for bioethics research are increasingly set by funding-agency strategic themes or by science collaborators and not by the bioethics researchers themselves. Although not all investigator-driven research is necessarily in the public interest, at least some of it is, and so there is an argument to be made to protect and promote investigator-driven bioethics research (particularly where the investigators are responsive to the needs and interests of the public).

Books and lengthy academic papers—This is the flip side of the issue of publishing in science journals mentioned earlier. When bioethics researchers write many short papers for science journals with high impact factors, then we don't write as many books and lengthy academic papers published in our own disciplinary journals. Yet length is essential for much of the complex ethical analysis that is actually required to advance understanding. The shift to science journals changes the nature and quality of the discussion. When we reduce the number of books and lengthy academic papers, we ultimately diminish the intellectual value and legitimacy of our field. This is, of course, not to say that bioethics researchers should not publish in science journals. There is an essential role for the translation and dissemination of research results in formats and fora

that reach across disciplines and sectors. However, knowledge translation should not be confused with knowledge production, and knowledge production in bioethics often requires the length afforded by books and very high word counts.

What we say and don't say

An interesting illustration of one concern about what we as bioethics researchers say comes from a comparison of the media content generated by bioethics researchers on genetics, genomics, and stem cell research in contrast to the media content generated by bioethics researchers on the increasing threats to the public health system in Canada. A number of bioethics researchers were very much out in public when governments sought to restrict the activities of scientists (e.g., the regulation of research involving human embryos),¹⁴ but where were they when the *Chaoulli* decision¹⁵ came down? The concern is whether, by shaping what researchers specialize in, the sources and features of money in bioethics research affect what topics bioethics researchers are qualified to speak out about.

Another concern about what we as bioethics researchers say is whether there is a pro-funder bias or apprehension of bias in our communication. Are we, or are we seen to be, pro-funder (or pro the funders' interests or objectives)? In response to skeptics on this, I would offer a question and a comment: (1) why would funders provide funds the way they do if doing so didn't work (i.e., advance their interests or objectives)? and (2) physicians thought that their prescribing patterns weren't affected by detailers and other industry "interventions," but they clearly were. As noted earlier, positive results biases have been well-demonstrated now in comparisons of research funded by industry with research not funded by industry (Bekelman, Yan, and Gross 2003; Lexchin et al. 2003). We should not wear the same blinders in the bioethics research community.

The sources and features of money in bioethics research may also affect what we don't say. Because of the need for money and the fact that much of the money that is available is encumbered or requires embedding or matching funds, bioethics researchers may be unwilling to say the following:

Matters covered in confidentiality clauses—The issue of confidentiality clauses in science research has received a great deal of attention (Thompson, Baird, and Downie 2001).¹⁶ There has been much discussion, for example, about the balancing of the interests of companies in protecting proprietary information prior to obtaining a patent against the interests of research participants in receiving information about harms that are discovered in the course of a research study. However, little attention has been paid to confidentiality clauses in bioethics re-

search. And yet, some of the worst clauses I have seen have been in contracts given to bioethics researchers to sign. For example, some bioethics researchers in Canada agreed, in the context of research embedded in a large science project, to be bound by an agreement in which the parties were required to not disclose any confidential information without the prior written consent of the other party; “confidential information” was any information designated as confidential by one party and provided to the other party. The agreement also included up to a six-month delay of the publication of research results by the bioethics researchers.¹⁷

Statements critical of employers—In part because of the structures within which bioethics researchers work (which in turn are partially a result of funding issues as noted earlier in the paper), bioethics researchers do not always have academic freedom; sometimes they are employed in faculties of medicine or in hospitals without the academic freedom protection of tenure. Without such protection, they may feel constrained from speaking out about the results of their research. Consider, for example, a bioethics researcher who comes to the conclusion that donation after cardiac death (DCD)¹⁸ is neither ethical nor legal. If she works in a health center that has implemented DCD, will she be willing and able to speak out against it?

Statements critical of current (or potential future) funders and current (or potential future) science collaborators—Will bioethics researchers self-censor in an effort to build or maintain relationships with funders and collaborators? Evidence of this is, for obvious reasons, difficult to find—is silence due to agreement or to self-censorship?

This discussion of the possible effects of money on bioethics research leads to a set of concerns about money and bioethics research.

Questions and concerns about money and bioethics

Based on the preceding exploration of the features, sources, and effects of money on bioethics research, I am left with a set of questions.

First, are we witnessing an unjust expenditure of resources within bioethics research? For example, what might the \$33.5 million spent on GE³LS by Genome Canada have accomplished if spent instead on ethics research related to health care and the disempowered in Canada (e.g., the failure to meet the health needs of many disadvantaged minorities or the privatization of health care)?

Second, are we witnessing an unjust expenditure of resources more generally (beyond Canada and beyond bioethics)? The money spent by Genome Canada (and its matching funders) on GE³LS could provide health care for one

year for 11 million people from Burundi or 5.5 million Ethiopians. What could \$33.5 million do for suicide prevention in aboriginal communities in Canada?

Third, are we giving value for money? Can we really give good value for \$33.5 million for GE³LS research? How many qualified researchers are there in bioethics in Canada? How many are doing this work? How many are experts in the field? How many hours are there in a day?

The preceding exploration also leads me to a set of concerns about the effects of money on bioethics research. Will our research be of less relevance for the vulnerable? Will we have less independence? Will we have and deserve less credibility? Will we have and deserve less respect? Ultimately, and most importantly, will we be less able to make a positive difference to the lives of those who most need our help?

New directions

In response, the bioethics research community could take a number of steps.

First, we could be more aware of our contexts of privilege (both relative to residents of our own countries and to individuals in other countries) and explore our derivative obligations.

Second, we could rethink our needs. We can easily get caught up and think that we need what we really just desire.

Third, we could expose the structures that construct/sustain needs (e.g., setting up centers and institutes without hard money so that there is a never-ending requirement to generate funds).

Fourth, we could be more aware of the potentially negative effects of money in bioethics research, particularly:

- Industry funding of bioethics researchers and institutions
- Sources of funding in addition to industry
- Effects in addition to co-opting
- Effects of embedding
- Effects of the absence of tenure or similar protections for academic freedom

Fifth, we could explore ways to better balance the positive and negative effects of money in bioethics research, particularly:

- Require meaningful transparency of funding (personal and institutional)—including disclosure of all amounts, sources, and purposes—whenever disseminating the results of bioethics research (in whatever the fora)¹⁹
- Establish standards around conduct, working conditions, funding conditions, and institutional structures for bioethics researchers²⁰
- Promote and protect academic freedom for bioethics researchers²¹
- Lobby for core funding for bioethics institutes and centers
- Promote collaboration models between scientists and bioethics researchers that do not create financial (inter)dependence
- Lobby for greater emphasis on investigator-driven, non-partnered, non-embedded research funding²²

If we do nothing, we will lose the moral authority or even basic legitimacy with respect to critiquing the power of money in science and medical research. If we do something, we could lead by example, and we could regain the capacity to make a positive difference in the world. We are good at throwing stones but, as the saying goes, people who live in glass houses. . . . It is beyond time to move out of our glass houses.

Notes

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1. The Canadian Institutes of Health Research (CIHR) is the Government of Canada's health research funding agency. The CIHR is comprised of thirteen "virtual" institutes (e.g., The Institute of Cancer Research) that coordinate funding according to the CIHR mandate "to excel, according to internationally accepted standards of scientific excellence, in the creation of new knowledge and its translation into improved health for Canadians, more effective health services and products and a strengthened Canadian health care system," <http://www.cihr-irsc.gc.ca/> (accessed January 26, 2009). The Canadian Foundation for Innovation (CFI) "is an independent corporation created by the Government of Canada in 1997 to fund research infrastructure. The CFI's mandate is to strengthen the capacity of Canadian universities, colleges, research hospitals, and non-profit research institutions to carry out world-class research and technology development that benefits Canadians," <http://innovation.ca> (accessed January 26, 2009).

2. The Stem Cell Network is a non-profit corporation formed in 2001. The SCN is part of Canada's Networks of Centres of Excellence, and it provides targeted research funding aimed at "enabling the translation of stem cell research into clinical applications, commercial products and public policy," <http://www.stemcellnetwork.ca/> (accessed January 26, 2009). Genome Canada is a non-profit organization mandated by the Canadian Government to "develop and implement a national strategy for supporting large-scale genomics and proteomics research projects for the benefit of all Canadians," <http://www.genomecanada.ca/> (accessed January 26, 2009).

3. For example, CIHR, Genome Canada, the Stem Cell Network, the Canadian Biotechnology Advisory Committee, the Huntington Society of Canada, and the Kidney Foundation of Canada.

4. This information was available on the Stem Cell Network website (www.stemcellnetwork.ca) in September 2008; however, as of January 26, 2009, it appears to have been removed from the site.

5. It is difficult to determine precisely the amount of money spent by CIHR on what can be characterized fairly as ethics research. If one searches the funded research database using the single term "ethics," the results are seriously over-inclusive—ethics can be a very peripheral part of a large science project and yet be included in the search results. In an effort to compare apples with apples (with respect to the comparators cited above), I therefore restricted my search to those grants handled by the Ethics, Law, and Humanities (ELH) peer review committee.

6. Based on all grants in the SSHRC-funded research database having "bioethics" as a keyword from 1998 to 2008. Again seeking consistency with other comparators, graduate student awards were not included.

7. For example, when one searches "ethics" on the CIHR-funded research database and does not limit the projects included to those handled by the ELH peer review committee, the funding jumps from \$6,519,738 to \$62,492,344.

8. Bill C-13, *Canadian Institutes of Health Research Act*, 2nd sess., 36th Parliament, 1999–2000 (assented to 13 April, 2000), 48–49 Elizabeth II, c.6.

9. *Canadian Dictionary of the English Language* (Toronto: International Thomson Publishing, 1998).

10. I should note here two difficulties associated with gathering evidence of the effects of money on bioethics research. First, a great deal of relevant information is not available. For example, the amounts and purposes of the money involved are not transparent. Many researchers do not include such information in their CVs available online. Second, it can be (or have the appearance of being) dangerous

to engage in such research. I was told that after I had given a talk that raised questions about competing interests and obligations for health law and policy researchers, the following comment was made in relation to my talk (among a group of researchers in the field who were together): “Her career is over.” Imagine the chilling effect of such a comment on me and on any other researcher who heard about it—these were people who could have a direct impact on my future access to research funding and career opportunities.

11. I compared the venues and page lengths of publications of two illustrative Canadian researchers—one known for doing a lot of embedded/encumbered research and one known for not doing a lot of it. Both are considered highly accomplished researchers. The one who does a lot of embedded/encumbered research published 49 percent of the time in science or medicine venues and 51 percent of the time in ethics, law, and social issues (ELSI—a common category for bioethics research) venues with an average of thirteen pages per publication. The one who does not do a lot of embedded/encumbered research published 9 percent of the time in science or medicine venues and 91 percent of the time in ELSI venues with an average of twenty-six pages per publication. Of course, a more comprehensive review of the literature and practice would be required to press this point, and it would require the cooperation of a number of bioethics researchers (so as to be able to determine levels of participation in embedded/encumbered research).

12. For an illustrative example, see the table re: publications, found in the CIHR Common CV module at www.commoncv.net (accessed January 26, 2009). A two-page article counts as much as a fifty-page article. For some of the problems with transferring metrics from science to non-science disciplines, see, e. g., the reaction to the European Reference Index for the Humanities, <http://www.corporeality.net/museion/2008/07/17/humanities-journals-under-threat-from-the-european-research-bureaucracy-erih> (accessed January 26, 2009). For a discussion of the problems with impact factors see Richard Smith, “Commentary: The power of the unrelenting impact factor—Is it a force for good or harm?” *International Journal of Epidemiology* 35 (5) (2006): 1129–30.

13. In a search conducted by a professional business librarian, only the following information about this company’s executives could be found: “Jeffrey L. Sturchio, Vice President, External Affairs, Human Health [Merck & Co. Inc.] Jonathan Kay, Editorials Editor of the National Post Newspaper Adrian Ivinson, Director, Harvard Center for Neurodegeneration and Repair, Harvard Medical School.” Netvention Company Profiles. Generate, Inc. (2007). Netvention Com-

pany Profiles: *The Genome Policy Program*. Retrieved September 29, 2008, from Lexis-Nexis Academic database.

Another source listed Jeffrey Sturchio, Adrian Ivinson, Peter Singer, Alan Bernstein, and Roderick McInnes as the “Genome Policy Program Executives,” <http://www.baltimore.bizjournals.com> (accessed January 26, 2009).

14. *Assisted Human Reproduction Act*, 2004, c.2.

15. *Quebec Attorney General v. Chaoulli* [2005] 1 S.C.R. 791, 2005 SCC 35.

16. For a detailed discussion of the Canadian case that received the most attention and precipitated significant changes in practice, see Jon Thompson, Patricia Baird, and Jocelyn Downie, “The Olivieri Report: The complete text of the report of the independent inquiry commissioned by the Canadian Association of University Teachers” (Toronto: James Lorimer and Company Ltd., 2001).

17. Draft agreement on file with the author.

18. DCD involves the removal of organs for the purposes of transplantation following determination of death according to cardiac criteria rather than neurological criteria (cardiac vs. brain death).

19. Journal editors could take first steps toward this goal by requiring disclosure of all funds (whether for the particular paper being published by them or not) by bioethics researchers and making the information accessible to the public through the journal websites or a central database, housed publicly on the Web, which researchers were required to keep complete and current as a condition of publishing in participating journals.

20. See, e.g., the work of the Canadian Bioethics Working Group on Working Conditions for Bioethics in Canada, <http://www.bioethics.ca/publications-ang.html> (accessed January 26, 2009).

21. See, e.g., policy statements on academic freedom, <http://www.caut.ca> (accessed January 26, 2009).

22. E.g., an increase in open operating grants from CIHR (www.cihr-irsc.gc.ca) and SSHRC (www.sshrc.ca) and an expansion rather than a reduction in Canada Research Chairs (www.chairs.gc.ca).

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