Published in final edited form as:
AJOB Prim Res. 2012 January 1; 3(3): 51–60. doi:10.1080/21507716.2012.678550.

Funding and Forums for ELSI Research: Who (or What) is Setting the Agenda?

Clair Morrissey and
Occidental College

Rebecca L. Walker
University of North Carolina at Chapel Hill

Abstract

Background—Discussion of the influence of money on bioethics research seems particularly salient in the context of research on the ethical, legal and social implications (ELSI) of human genomics, as this research may be financially supported by the ELSI Research Program. Empirical evidence regarding the funding of ELSI research and where such research is disseminated, in relation to the specific topics of the research and methods used, can help to further discussions regarding the appropriate influence of specific institutions and institutional contexts on ELSI and other bioethics research agendas.

Methods—We reviewed 642 ELSI publications (appearing between 2003–2008) for reported sources of funding, forum for dissemination, empirical and non-empirical methods, and topic of investigation.

Results—Most ELSI research is independent of direct grant-based funding sources; 66% reported no such sources of funding. The National Human Genome Research Institute (NHGRI) is the most dominant source of funding; 16% of publications acknowledged at least one source of NHGRI grant funding. Funding is acknowledged more frequently in empirical than non-empirical publications, and more frequently in publications in public health journals than in any other ELSI research dissemination forums. Dominant research topics vary by publication forum and by reported funding.

Conclusions—ELSI research is surprisingly independent of direct grant-based funding, yet correlations are apparent between this type of funding and publication placement, topics addressed, and methods used, implying a not insignificant influence on ELSI research agenda-setting. However, given the relatively low percentage of publications acknowledging external grant-based funding, as well as other significant correlations between publication placement and topics addressed, additional institutional contexts, perhaps related to professional advancement or valuation, may shape research agendas in ways that potentially exceed the direct influences of grant-based funding in this area. In some cases, grant-based funding may actually counter other potentially problematic institutional influences.

Keywords

Genomics [Ethics]; National Human Genome Research Institute (U.S.); Ethics, Professional

Address correspondence to Clair Morrissey, PhD, Assistant Professor, Occidental College, 1600 Campus Road, Los Angeles, California 90041, USA. cmorrissey@oxy.edu.

INTRODUCTION

Discussion of the influence of money on bioethics research and scholarship is limited compared to the robust literature within bioethics on the role of money in medicine and science. When the influence of money on bioethics *is* addressed, the discussion focuses primarily on whether it is appropriate for academic bioethicists to receive money from for-profit companies for "ethics-related services and research" (Downie 2009; Elliott 2001; Elliott 2005; Sharp et al. 2008; Sharpe 2002). However, as Carl Elliott points out, the heart of the question is "whether bioethicists might legitimately accept money from the bodies whose actions and policies they [are] commenting upon in their teaching, writing, consulting, and policymaking" (Elliott 2001, 9). This question does not draw a boundary around certain kinds of "bodies" as legitimate or illegitimate sources of funding, but rather asks us to consider what happens when bioethics researchers are paid by, and comment on, the same entities or bodies.

Research on the ethical, legal, and social implications (ELSI) of human genomics is unique within bioethics in having a dedicated government program – the ELSI Research Program – that supports both intramural and extramural work on these issues. Because the ELSI Research Program is part of the National Human Genome Research Institute (NHGRI), the potential tensions raised by researchers commenting (at least in part) on the activities of the entity that is also financially supporting them are highly salient and have not gone unnoticed1 (Andrews 1999; Callahan 1996; Yesley 2008). Programs with similar focus on genomic sciences, technologies, and practices have been developed internationally,2 and presumably raise similar tensions between the funding source and the possibility of independent critique (Caulfield 2005). At the same time, research and scholarship within bioethics addressing issues of ethical or broader social concern with regard to human genetics has flourished since before the start of the Human Genome Project (and hence before the ELSI Research Program) (Juengst 1991).

We ought to understand the *field* of "ELSI" research in terms of research and scholarship content, rather than a particular set of funding sources. In the same way that we would not want to define what counts as genomics research in terms of funding sources, we should not restrict what counts as ELSI research by conflating this developing field of scholarship with a particular government program. This raises a crucial question as to the extent and influence of funding within ELSI as a field. That question, thus far unaddressed, is a central focus of this paper.

Yet who or what shapes the ELSI research agenda is a question only partly addressed by looking at direct sources of research funding. As both Debra Debruin (2007) and Leigh Turner (2007) discuss, the entanglement of promotion, tenure, professional status, and salary within specific institutional settings is also highly significant for the bioethics researcher or scholar. Debruin writes, "If our livelihood depends on the support of biomedical institutions, then we may feel pressure to please our patrons….institutional forces may influence not only the topics we take up but also the analyses we provide of them" (Debruin 2007, 166). There is a similar issue regarding the dissemination of ELSI research: if the professional

[1]Although this potential tension is noted by commentators, in both the 2003 and 2011 NHGRI strategic visions for genomics research, ELSI research was integrated into the broader vision for genomic research, and explicit goals and understandings of the agenda for ELSI research were outlined (Collins et al. 2003; Green, Guyer and NHGRI 2011). This integration of ELSI research into the broader vision overlooks potential tensions arising from the fact that ELSI research may be critical of genomics research generally, or the NIH or NHGRI goals, more specifically.

[2]Examples of these programs include: Genome Canada - Ethical, Environmental, Economic, Legal and Social Issues (GE3LS) (http://www.genomecanada.ca/en/ge3ls/), Instituto Nacional de Medicina Genómica- Department of Legal Studies, Ethical and Social Research Directorate (http://www.inmegen.gob.mx/), and the Wellcome Trust - Ethics and Society Programme (http://www.wellcome.ac.uk/Funding/Ethics-and-society/index.htm).

status of ELSI researchers is, in part, determined by success publishing in medical or science journals, and if these journals tend to publish ELSI research engaging particular methods and/or topics, then the priorities of those publication forums will likely influence bioethics research agendas. For example, a research agenda may develop which emphasizes questions relevant to the professional goals of medicine or specific scientific advances, rather than more fundamental evaluations of the aims of biomedical science institutions themselves, or the relationship between science and society more generally (De Vries and Keirns 2008; Loewy 2002; Stevens 2000).

Our research analyzes literature published between 2003–2008 at the intersection of (1) ethics, or ELSI more broadly, and (2) human genetics or genomics. Elsewhere, we present an analysis of five types of ELSI research; a comprehensive list of the topics addressed in this literature; and information about the contributing authors' fields of training (Walker and Morrissey 2012). Here, we provide data on the extent and nature of funding within ELSI research and the forums for dissemination of this research and their relation to the selection of topics and the adoption of empirical or non-empirical methods. The results of our study are, on the one hand, surprising with respect to the relative independence of the field of ELSI research and scholarship from the ELSI Research Program and, on the other, confirmatory of certain expected relationships between funding, forums, and other features of ELSI research. At the same time, given the relatively low percentage of publications acknowledging external grant-based funding, as well as significant correlations between publication placement and topics addressed, it is arguable that institutional forces beyond external grant-based funding, perhaps related to professional advancement or valuation, may have even greater capacity to shape research agendas. In some cases, grant-based funding may counter other potentially problematic institutional influences.

While the data provided here cannot answer crucial underlying questions about the influence of money and institutional settings on what bioethics researchers espouse, or the depths to which they are willing to probe, it can provide a starting place for such conversations with respect to the field of ELSI research. And if, as some would seem to desire, the ELSI Research Program is seen a model for other arenas of science and medicine,[3] then it is incumbent upon bioethicists, who look so closely at the ways that money influences physicians and basic science researchers, to go into these potential new relationships with bioethics funders with eyes open to problems that may arise.

METHODS

We identified and reviewed publications addressing the intersection of ethics specifically, or ELSI more broadly, and human genetics or genomics released within a five-year period (2003–2008). This time frame reflects the completion of the human genome project in 2003 (U.S. Department of Energy) and the publication of the NHGRI 2003 vision for the future of genomic research. In order to accurately gauge the impact of the ELSI Research Program and other funding on the field of ELSI research generally, we sought to include work from diverse contributors. To that end, we utilized multiple sources capturing: (a) the work of people closely identified with the ELSI Research Program through the ELSI Archives (created by Case Western Reserve University's Center for Genetic Research Ethics and Law), Bio-Medical Ethics Reference Server (BMERS, hosted by Stanford University's Center for Integration of Research on Genetics and Ethics), and all other Centers for Excellence in ELSI Research (CEER) webpages; (b) research from the broader medical, social science, and other scientific literatures through Pubmed and Web of Science; and (c)

[3]While we are unaware of any appearance in print, this idea seemed to be promoted at both the most recent ELSI Congress (Chapel Hill, NC, 2011) and at the most recent Centers for Excellence in ELSI Research (CEERs) investigator meeting (Rockville, MD, 2011).

the work of humanities researchers and scholars (in particular book chapters) through the GenETHX database (hosted by the Bioethics Research Library at Georgetown University).

Variation in the search strategies was necessary given differences in the nature of the sources. A narrowly tailored Boolean search was used for Pubmed, Web of Science, and GenETHX; a keyword search was used for BMERS; all the references from the CEER webpages were collected by hand; and the ELSI Archives were searched by hand for relevant publications. When employed, search terms included variants and combinations of the terms “ethics,” “morality,” “ELSI,” “genomics” and “genetics.” Specific search strategies were developed with the help of health sciences research librarians at the University of North Carolina at Chapel Hill and at the Georgetown Bioethics Research Library. While our publication collection strategy was inclusive in terms of diverse contributors to the ELSI literature, ELSI relevant publications released during our five-year period that did not employ the terms “ethics,” “morality,” or “ELSI” *and* were not included in the ELSI databases or web pages consulted are not represented by this study.

The flow chart in Figure 1 tracks inclusion/exclusion processes generating the final group of articles and book chapters from the initial group of publications identified. All English language publications addressing human genetics or genomics and ethics or other ELSI-related work, such as book chapters; research/scholarship articles; or, where representing a substantial contribution to the literature, commentaries or (infrequently) editorials, were included in the study. Only topics that did not specifically address human genetics/genomics were excluded. The final sample of eligible publications was classified according to acknowledged sources of extra- or (infrequently) intramural funding and the forum in which it was published. Below we present these findings as well as their correlations with the topic of publication and the use of empirical or non-empirical methods.

RESULTS

Our initial searches identified 1,010 publications; and the final study population was comprised of 642 publications. Although all publications were English-language, the institutional affiliation of first authors indicates a transnational research community. Roughly 67% of the first authors for the publications in this study had primary institutional affiliations in North America, 25% in Europe, and 3% in each of Asia and Australasia; 1% were international entities not affiliated with a particular country. No first authors in this study had institutional affiliations in Africa or Central America.

Reported Sources of Funding

We found that 66% of the publications meeting inclusion criteria for our study did not report grant-based extramural or intramural sources of funding for any of the listed authors. Of the publications that *did* report such sources of funding for any authors, the NHGRI was the most dominant source; 16% of all publications in the study acknowledged at least one source of grant funding from the NHGRI. Governmental organizations other than the NHGRI (both within and outside the United States), along with non-profit organizations, were the next most frequently reported sources of funding.

Table 1 contains a more detailed presentation of the reported sources of funding across different categories of funding mechanisms: *NHGRI*, *Other US Gov*, *Non-US Gov*, *University*, *Non-Profit* and *Private*. The first three categories represent different public funding mechanisms for ELSI research: the National Human Genome Research Institute [*NHGRI*], all other divisions and departments within the United States Government [*Other US Gov*], and government based funding mechanisms outside the United States [*Non-US Gov*]. Some authors acknowledged extra- or intramural funding from specific universities or

university based research centers [*University]*, while others reported extramural funding from non-profit organizations such as the Kleberg Human Genetics Research Fund or the Robert Wood Johnson Foundation *[Non-Profit]*. Finally, while constituting a small proportion of the overall population (1%), some publications acknowledged funding from private organizations or corporations [*Private*]. Only one publication reported *only* private funding; all others reported grant funding from at least one other kind of funding source. For each publication, each reported grant or other extramural or intramural source of funding was recorded. As 14% of the publications reported multiple sources of funding, a single publication may have been counted as both, for example, *NHGRI* and *University*.

Because we could not determine in all cases whether funding reported as NHGRI was also ELSI Research Program funding, we did not separate out these two types of funding. Thus, we cannot be certain whether the funding reported as NHGRI was specific to ELSI research. At the same time, as discussed below, in verifying our data, we did identify publications in which listed authors did not report funding support for the ELSI publication in our study, but did receive NHGRI or other NIH grants for other science research during the relevant time period.

To verify the surprisingly low number of publications reporting a funding source, in particular from the NHGRI or ELSI Research Program, we further investigated a 10% random sample of those publications that did not report any source of funding (n=38). We searched within the NIH Research Portfolio Online Reporting Tools (RePORT) database for funding beginning in the year 2000 for all authors (n=67) associated with the randomly selected publications (http://report.nih.gov/). Sixteen of these authors, associated with 15 publications, had received some sort of NIH funding. We investigated each authors' funded projects to see whether it was likely that they failed to appropriately acknowledge funding for the publication that was included in our study. We found that in all but one case, it was implausible that the author failed to appropriately acknowledge funding. Funded projects were typically: (a) on different topics than the publication at issue (e.g., the funded project was on genetics and obesity in African Americans, but the publication was on genetic ancestry tracing and African identity); (b) addressed a different aspect of the topic than the publication (e.g., funding was for a social science study of the effects of genetic testing on families but the publication promoted a policy and educational agenda regarding genetic testing); or (c) occurred only after the publication date. Additionally, we found that some of the publications that did not report funding were commentaries or articles written by those with extensive funding in the genomic science question at issue, but without funding to conduct ELSI research specifically.

Publication Forum

The publications in our study were distributed among a wide variety of academic forums for communicating research. Bioethics journals and medical journals were the most common publication forums (29% and 25% of the publications, respectively). The least common publications forums were law journals (4% of the publications). Each publication was categorized into only one of the of the following seven publication forums: *Book Chapters*, *Bioethics Journals*, *Law Journals, Medical Journals, Public Health Journals, Science Journals and General Social Science or Humanities Journals*.

Some of these categories are more straightforward than others. For example, those publications categorized as *Book Chapters* were selections from edited anthologies published as books, and *Law Journals* includes publications in law reviews and other journals that primarily publish legal scholarship. Other categories involved more interpretative flexibility. *Bioethics Journals* are those that either self-describe as having a bioethics focus (in a mission statement, journal title, or elsewhere), or that publish research

at specific intersections of fields and/or topics standardly viewed as contributing to bioethics. For example, *Developing World Bioethics* and *Social Science & Medicine* are both bioethics journals according to this classification system. These journals may be most readily contrasted with, on the one hand, the *Social Science and Humanities Journals*, which publish broadly (e.g. beyond medicine or life science related topics and issues) in disciplines such as philosophy, sociology and anthropology, and *Medical or Science Journals* on the other, which publish broadly (e.g. beyond humanities, social science or legal scholarship) in medical research and clinical practice (including nursing and allied health research and practice) and the natural and life sciences.

Table 1 details relationships between funding and publication forums for the ELSI research and scholarship reviewed in our study. Publications in public health journals reported the highest average number of funding sources per article, and also more frequently reported sources of funding; 60% of articles published in public health journals reported at least one source of funding. Publications appearing in medical journals were the next most likely to report funding; 42% of articles published in a medical journal reporting at least one source of funding. Only 13% of book chapters reported funding, and less than a quarter of publications in law journals and science journals did so.

Empirical vs. Non-Empirical Methods

Within the ELSI research community, as well as the broader bioethics community, "conceptual" or "normative" scholarship and research is often contrasted with empirical work. This way of categorizing ELSI work may serve to demarcate methodologies, as well as to indicate appreciation for concerns about moving directly from what "is" the case to what "ought" to be the case.4 Elsewhere, we offer an expanded set of categories for classifying ELSI Research: *social science study report*, *broader ELSI focus*, *ethics focus*, *other normative focus*, and *policy recommendation* (Walker and Morrissey 2012). However, only the broader categories *empirical* and *non-empirical* were interestingly related to funding and forums. Thus, we collapsed the expanded set of categories for reporting purposes in this context. We understood *empirical* publications as those that reported on studies that adopted qualitative, quantitative, and/or mixed social science methodologies to examine ethics-related, ELSI or otherwise morally salient issues in genetics or genomics. For example, in an empirical study, Arar et al. (2005) assessed subjects' ability to recognize the risks and ethical issues of enrollment in family genetic studies (along with the relationship between recognition of risk and voluntary participation) through a series of structured and semi-structured interviews with individual potential participants.

As is reported in Table 1, 78% of empirical publications acknowledged at least one funding source, while only 25% percent of non-empirical publications reported funding. Empirical publications also reported significantly more sources of funding per publication than the non-empirical publications. Of those publications that reported at least one source of funding from the NHGRI, 52% were classified as empirical;5 yet only 17% of the publications in our study were classified as empirical publications. In comparison, of those publications reporting funding from a US government source other than the NHGRI, only 30% were

[4]Although adopting this convention for purposes of elucidating these findings, we believe it is important to note that the terms "conceptual" and "normative" are neither synonymous nor readily defined in ways that indicate a single approach to ELSI research. For example, "conceptual" research may not have normative aims and, furthermore, empirical work may include normative conclusions. In addition to the lack of any necessary alignment between conceptual methods and normative goals, concerns within the ELSI literature regarding the appropriate relationship between empirical work and normative conclusions are not necessarily congruent with the set of meta-ethical concerns reflected variously as the "naturalistic fallacy," the "is/ought gap" or the "fact/value distinction." For a discussion of these frequently cited metaethical considerations and their (perceived) importance for bioethics, see deVries and Gordijn (2009).

classified as empirical publications. Similarly, only 22% of the publications reporting funding from a non-US government source were empirical.

Topics

Publications in the study were categorized according to a list of topics that was developed using the session headings for the 2008 ELSI Congress, "Translating ELSI: Global Perspectives in Research on the Ethical, Legal and Social Implications of Human Genome Research," held May 1–3 in Cleveland, Ohio. Additional topics were added, and others collapsed, as necessary to effectively capture the literature included in our study. We offer a comprehensive list of 18 specific topics addressed within publications in our study elsewhere (Walker and Morrissey 2012). Here, we present data on the relationships between specific topics and sources of funding and publication forum.6

Table 2 reports the specific topics most prevalent across the different forums for publication and across the different categories of reported funding. There is significant divergence between the most frequently addressed topics within the various forums for communicating ELSI research and scholarship as well as in the relative dominance of the most frequently addressed topic within each publication forum. There are also important differences between the most frequently addressed topics depending on whether the publication acknowledges funding and what sort of funding.

The most prevalent topics among publications that reported some source of funding were *genomic research and the public* and *genetics and race*. The topic *genomic research and the public* included work focused on the concerns, uptake, understandings, or other perspectives of the public (or different publics) with respect to particular aspects or practices of genomics or of genomics generally. For example, Mountcastle-Shah et al. (2003) reports the development of an instrument utilizing objective criteria for assessing the quality of media stories about genetic discoveries relevant to human diseases, while Benner calls for the "demystification of genomic science and more realistic public understanding of the possibilities and promise of genomic science" (2003, 261). The topic *genomic research and the public* thus lends itself well to empirical investigation but is not defined by the use of such methods. It was also the most prevalent topic among those publications reporting at least one source of funding from the NHGRI, and among the most prevalent topics of publications reporting funding from non-US Government mechanisms, and Universities. Other prevalent topics common to multiple funding mechanisms were *genetics and race* and *biorepositories*.

The most prevalent topics among publications not reporting funding were *genomics generally* and *enhancement*. The topic *genomics generally* captures publications that address genomic advances or genome science broadly. For example, Wachbroit (2003) explores the relationship between genetic science advancement, conceptions of biological 'normality,' and judgments about what it means to be human.

---

[5]Table 1 does not report the information in this form, which is a simple calculation based on the information reported there. To determine the proportion of *empirical* NHGRI supported publications we divided the number of publications categorized as empirical that reported at least one source of NHGRI funding (53) by the total number of publications that reported at least one source of NHGRI funding (102). A similar calculation was done to determine the proportion of empirical US government supported publications and non-US government supported publications.

[6]The full list of topics contains the 3 more general categories of "other genomic research", "other genetic testing", and "other reproductive genetics" which serve to capture publications addressing topics within these areas broadly or specific subtopics within these areas that are not otherwise represented on the list. We have not included these categories in the correlations detailed here as they are less meaningful out of context of the complete list of topics.

DISCUSSION

Most of the publications in our study did not report grant-based extramural or intramural sources of funding.7 Among those publications that did indicate such sources of funding, the dominant funding mechanisms were governmental, particularly the NHGRI. For those who are primarily concerned with the ways in which bioethics research and scholarship may be influenced by for-profit or other private entity interests, these results may be comforting (Elliott 2001; Sharp et al. 2008; Turner 2004). However, given the ELSI Research Program's institutional relationship to the genome-science enterprise as itself part of the NHGRI, there is also a need for critical discussion of the extent to which the ELSI Program (and, to some extent, its international counterparts), is or ought to be setting the agenda for research at the intersection of important social issues and human genomics.

One potential explanation for the observed relative independence of ELSI research and scholarship from grant-based funding is the high percentage (73%) of non-empirical publications in our study, of which only a quarter reported any funding. While only 17% of the total publications, 78% of empirical methods publications reported at least one source of funding. The relative costliness of empirical research is one likely factor contributing to this difference, but another potential explanation for the relatively low proportion of non-empirical publications reporting funding is the research priorities of funding institutions. In this regard it is important to emphasize the differences between NHGRI-funded publications and those publications acknowledging support from government agencies other than the NHGRI. While over half of publications acknowledging funding from NHGRI reported on studies using empirical methods, publications acknowledging funding from other US government agencies as well as those reporting funding from non-US government funding agencies were overwhelmingly non-empirical (70% and 78% respectively).8 In other words, since the NHGRI is the most common funder of ELSI research, the result is a research agenda that may be more empirically driven than if other governmental programs were more frequent funders of ELSI work.

Remaining cognizant of how institutional settings shape research, it is interesting that while dominant topics varied by forum for research and scholarship dissemination, the general focus of ELSI work on topics of particular interest to advantaged populations did not. For example, the focus on *genomics and clinical practice* within ELSI publications in medical journals may reflect the priorities of those who already have unproblematic access to healthcare.9 In contrast only 2% of the ELSI publications in medical journals addressed the topic of *genomics and health disparities*. Similarly, in science and social science and humanities journals, discussions of *intellectual property* were prevalent. This topic may speak more to the interests of scientists than either society more broadly or populations marginalized with respect to genomic research. By way of contrast, the topic *genomic*

[7]As an additional check on our surprising results regarding the extent of reported funding for ELSI research and scholarship, we also looked independently at the percentage of research articles from periodicals that acknowledged funding. This did result in a change in the results, from 34% of publications reporting funding to 41% of publications. At the same time, we believe it is important to note that 13% of the book chapters in our study *did* indicate at least one source of funding and, while it is likely that the lower rates of funding acknowledged in commentaries result from different expectations regarding reporting of funding within this type of publication, we cannot tell whether the lower rates of reported funding within book chapters reflect different norms of reporting funding or simply a different rate of funding associated with the types humanities research and scholarship that are more commonly found in books.

[8]Table 2 does not report the information in this form, which is a simple calculation based on the information reported there. To determine what proportion of the publications supported by funding from US and non-US government agencies was non-empirical, we divided the number of non-empirical publications that reported such funding (27 and 46, respectively) by the total number of publications that reported such funding (39 and 59, respectively). See also footnote 5.

[9]That medical journals disproportionately publish articles on research topics relevant to the relatively wealthy is not a novel observation. Studies suggest, for example, that global health inequalities and diseases associated with poverty are not frequently discussed in medical journals (Horton 2003; Rochon et al 2004; Sumathipala, Siribaddana, and Patel 2004; Turner 2007).

research with indigenous communities was addressed by only 2% of the ELSI publications in the science journals and 4% of ELSI publications in the social science and humanities journals. Similarly, *genetic enhancement* was a dominant topic within book chapters and law journals, and publications in bioethics journals tended to address *biorepositories*. Neither topic seems particularly pressing for less advantaged individuals or communities.

At the same time, our study indicates that governmental funding agencies have the potential to enhance research on specific topics of investigation that may otherwise receive less attention. Just prior to the five-year period of our study, the ELSI Research Program issued a request for applications (RFA) for "Studies of the Ethical, Legal, and Social Implications of Human Genetic Variation Research for Individuals and Diverse Racial and Ethnic Groups" (NHGRI 2002). Reflecting this research priority, 11% of the publications reporting grant funding from the NHGRI primarily discussed *genetics and race*. These publications accounted for 24% of the total publications in this study centrally addressing the topic of *genetics and race*. Importantly, a number of these publications were critical of the genomic science interest in genetic variation research, and more broadly, of the ways in which genomic science was engaging with, and potentially reifying, concepts of race.

Our study has important limitations. Two types of publications in particular may be underrepresented: (1) publications focused narrowly on intersections of socially salient issues with regard to human genomics other than ethics (for example, law and genomics or public policy and genomics) that did not also engage with ethics or a broader ELSI discussion, and (2) social science methods studies that addressed morally salient issues with human genomics research, practices or technologies but did not use the terms "ethics," "morality," or "ELSI" (or variations thereon). In addition, although the sources used for identifying ELSI literature published during the 2003–2008 time frame did allow us to capture a great many publications authored by researchers outside the United States, the English-language restriction along with our use of sources prominent within the United States research context likely privileged the inclusion of publications written by researchers in the United States, and, to a lesser extent, Western Europe. Our ability to generalize about public funding outside the United States is thereby limited.

To determine funding sources, we relied on author self-report, although we also included a mechanism for verifying these results as discussed above. As some publication forums do not require authors to report funding, sources of funding may be underreported in our study. The absence of a common practice for distinguishing which authors are supported by which sources of funding, or the government institutional or program level at which the funding occurred, also prevented specification of ELSI Research Program funding separately from NHGRI funding. Thus, we cannot be certain whether the funding reported here as "NHGRI" is specifically for ELSI research and scholarship.

Finally, direct grant funding is only part of the picture when it comes to assessing institutional influences on the ELSI research agenda. Also important are measures for less direct funding (Evans 2008; Resnik 2008) as well as the broader issues of institutional context influencing tenure, promotion, and professional status. While we have included data on where ELSI research is disseminated and how this relates to research topics, these measures can only shed a small ray of light on these larger questions of institutional and professional context and influence.

Nearly a decade ago, while addressing the question of corporate funding, Virginia Sharpe raised the following questions to the broader bioethics community: "Who is it that bioethicists and bioethics institutions should serve? For whom should we act as agents or intermediaries? To whom are we accountable?" (2002, 25). These are not questions that we

settle once and for all, but are rather questions on which we must regularly reflect. In the context of ELSI research, the issues are less about corporate funding and more about the influence of government funded genomic sciences institutes on the one hand and the complex institutional and professional forces that guide researchers, whether grant funded or not, toward topics of particular interest to affluent populations (including genomic research itself) on the other. Still, our findings show that government funding might help to set an agenda more friendly to the interests of populations traditionally underserved by genomic science.

Acknowledgments

We are grateful for the support of the UNC Center for Genomics and Society, which has funded this research through an NIH Centers for Excellence in ELSI Research grant (number 1P50 HG004488-01) to Gail Henderson (PI). We thank Kelsey Palghat, Warren Whipple, Martha King, and Allen Buansi for their assistance in coding. We also thank the UNC Odum Institute as well as Gail Henderson, Debra Skinner, and Michele Easter for advice regarding research methods. Finally, we thank Eric Juengst and Nancy King for substantive helpful discussions regarding the field of ELSI research.

Works Cited

Andrews, LA. The clone age. New York, NY: Henry Holt and Company; 1999.

Arar NH, Hazuda H, Steinbach R, Arar MY, Abboud HE. Ethical issues associated with conducting genetic family studies of complex disease. Annals of Epidemiology. 2005; 15(9):712–719. [PubMed: 16157258]

Benner P. Creating a more responsible public dialogue about the social, ethical, and legal aspects of genomics. American Journal of Critical Care. 2003; 12:259–261. [PubMed: 12751401]

Bio-Medical Ethics Reference Server. [Accessed on June 1, 2008] Stanford University Center for Integration of Research on Genetics and Ethics. http://bmers.stanford.edu. *Website no longer available*.

Callahan D. Bioethics, our crowd, and ideology. Hastings Center Report. 1996; 26(6):3–4.

Caulfield T. An independent voice?: Conflicts of interest and research on ethical, legal and social issues. Health Law Review. 2005; 13(2 & 3):114–116. [PubMed: 16459424]

[Accessed on June 1, 2008] Center for Genetics Research Ethics and Law. http://www.cgreal.org/

Center for Genomics & Healthcare Equality. University of Washington; http://depts.washington.edu/cghe/

Center for Genomics & Society at UNC-Chapel Hill. University of North Carolina at Chapel Hill; http://genomics.unc.edu/genomicsandsociety/

Center for Integration of Research on Genetics and Ethics. Stanford University; http://cirge.stanford.edu/

Collins FS, Green ED, Guttmacher AE, Guyer MS. A vision for the future of genomics research. Nature. 2003; 422:835–847. [PubMed: 12695777]

Debruin, DA. Ethics on the inside?. In: Eckenwiler, LA.; Cohn, FG., editors. The ethics of bioethics: Mapping the moral landscape. Baltimore, MD: Johns Hopkins University Press; 2007. p. 161-169.

Department of Energyd. Major Events in the U.S. Human Genome Project and Related Projects. http://www.ornl.gov/sci/techresources/Human_Genome/project/timeline.shtml

De Vries R, Gordijn B. Empirical ethics and its alleged meta-ethical fallacies. Bioethics. 2009; 23(4): 193–201. [PubMed: 19338520]

De Vries R, Keirns CC. Does money make bioethics go ‘round? American Journal of Bioethics. 2008; 8(8):65–67. [PubMed: 18802872]

Downie J. Glass houses: The power of money in bioethics research. International Journal of Feminist Approaches to Bioethics. 2009; 2(2):97–115.

Elliott C. Throwing a bone to the watchdog. Hastings Center Report. 2001; 31(2):9–12. [PubMed: 11478117]

Elliott C. Should journals publish industry-funded bioethics articles? The Lancet. 2005; 366:422–424.

ELSI Archives. [Accessed on May 1, 2008] Center for Genetic Research Ethics and Law, Case Western Reserve University. www.cgreal.org. *Website no longer available*.

Ethics and Society. [Accessed on March 13, 2012] Wellcome Trust. http://www.wellcome.ac.uk/Funding/Ethics-and-society/index.htm

Evans JH. In search of a measure of industry funding. American Journal of Bioethics. 2008; 8(8):59–60. [PubMed: 18802868]

Genome Ethics, Law & Policy. Duke Institute for Genome Sciences & Policy. Duke University; http://www.genome.duke.edu/research/society/

GE^{3}LS, Genomics & its Ethical, Economic, Environmental, Legal and Social Aspects. Genome Canada: http://www.genomecanada.ca/en/ge3ls/

GenETHX. Bioethics Research Library at Georgetown University. Georgetown University;

Green ED. M. S. Guyer and National Human Genome Research Institute. Charting a course for genomic medicine from base pairs to bedside. Nature. 2011; 470:204–213. [PubMed: 21307933]

Horton R. Medical journals: Evidence of bias against the diseases of poverty. The Lancet. 2003; 361:712–713.

[Accessed on March 13 2012] Instituto Nactional de Medicina Genómica. http://www.inmegen.gob.mx/

Juengst ET. The human genome project and bioethics. Kennedy Institute of Ethics Journal. 1991; 1:71–74. [PubMed: 10113820]

Loewy EH. Bioethics: Past, present, and an open future. Cambridge Quarterly of Healthcare Ethics. 2002; 11(4):388–397. [PubMed: 12360709]

Mountcastle-Shah E, Tambor E, Bernhardt BA, et al. Assessing mass media reporting of disease-related genetic discoveries: Development of an instrument and initial findings. Science Communication. 2003; 24(4):458–478.

National Institutes of Health Research Portfolio Online Reporting Tools (RePORT). U.S. Department of Health & Human Services; http://report.nih.gov/

NHGRI. National Human Genome Research Institute. Studies of the ethical, legal, and social implications (ELSI) of human genetic variation research for individuals and diverse racial and ethnic groups (RFA-HG-02-003). 2002. Available at: http://grants.nih.gov/grants/guide/rfa-files/RFA-HG-02-003.html, retrieved 16 November 2011.

Pubmed. U.S. National Library of Medicine. National Institutes of Health; http://www.ncbi.nlm.nih.gov/pubmed/

Resnik DB. Hidden sources of private industry funding. American Journal of Bioethics. 2008; 8(8):60–61. [PubMed: 18802869]

Rochon PA, Mashari A, Cohen A, et al. Relations between randomized controlled trials published in leading general medical journals and the global burden of disease. Canadian Medical Association Journal. 2004; 170:1673–1677. [PubMed: 15159365]

Sharp RR, Scott AL, Landy DC, Kicklighter LA. Who's buying bioethics research? American Journal of Bioethics. 2008; 8(8):54–58. [PubMed: 18802867]

Sharpe VA. Science, bioethics and the public interest: On the need for transparency. Hastings Center Report. 2002; 32(3):23–36. [PubMed: 12085511]

Stevens, MLT. Bioethics in America: Origins and cultural politics. Baltimore: Johns Hopkins University Press; 2000.

Sumathipala AS, Siribaddana S, Patel V. Under-representation of developing countries in the research literature: Ethical issues arising from a survey of five leading medical journals. BMC Medical Ethics. 2004; 5:5.

Turner L. Bioethic$ inc. Nature Biotechnology. 2004; 22(8):947–948.

Turner, L. Global health inequalities and bioethics. In: Eckenwiler, LA.; Cohn, FG., editors. The ethics of bioethics: Mapping the moral landscape. Baltimore, MD: Johns Hopkins University Press; 2007. p. 229-240.

U.S. Department of Energy. [Accessed on March 13, 2012] Major Events in the U. S. Human Genome Project and Related Projects. http://www.ornl.gov/sci/techresources/Human_Genome/project/timeline.shtml

Wachbroit, R. Normal humans, human nature, and genetic lessons. In: Gehring, VV., editor. Genetic prospects: Essays on biotechnology, ethics and public policy. Lanham, MD: Rowman and Littlefield Publishers; 2003. p. 51-60.

Walker RL, Morrissey C. Charting ELSI's future course: Lessons from the recent past. Genetics in Medicine. 2012; 14(2):259–267. [PubMed: 22261758]

Web of Science. Thompson Reuters; http://apps.isiknowledge.com

Yesley MS. What's ELSI got to do with it? Bioethics and the human genome project. New Genetics and Society. 2008; 27(1):1–6.

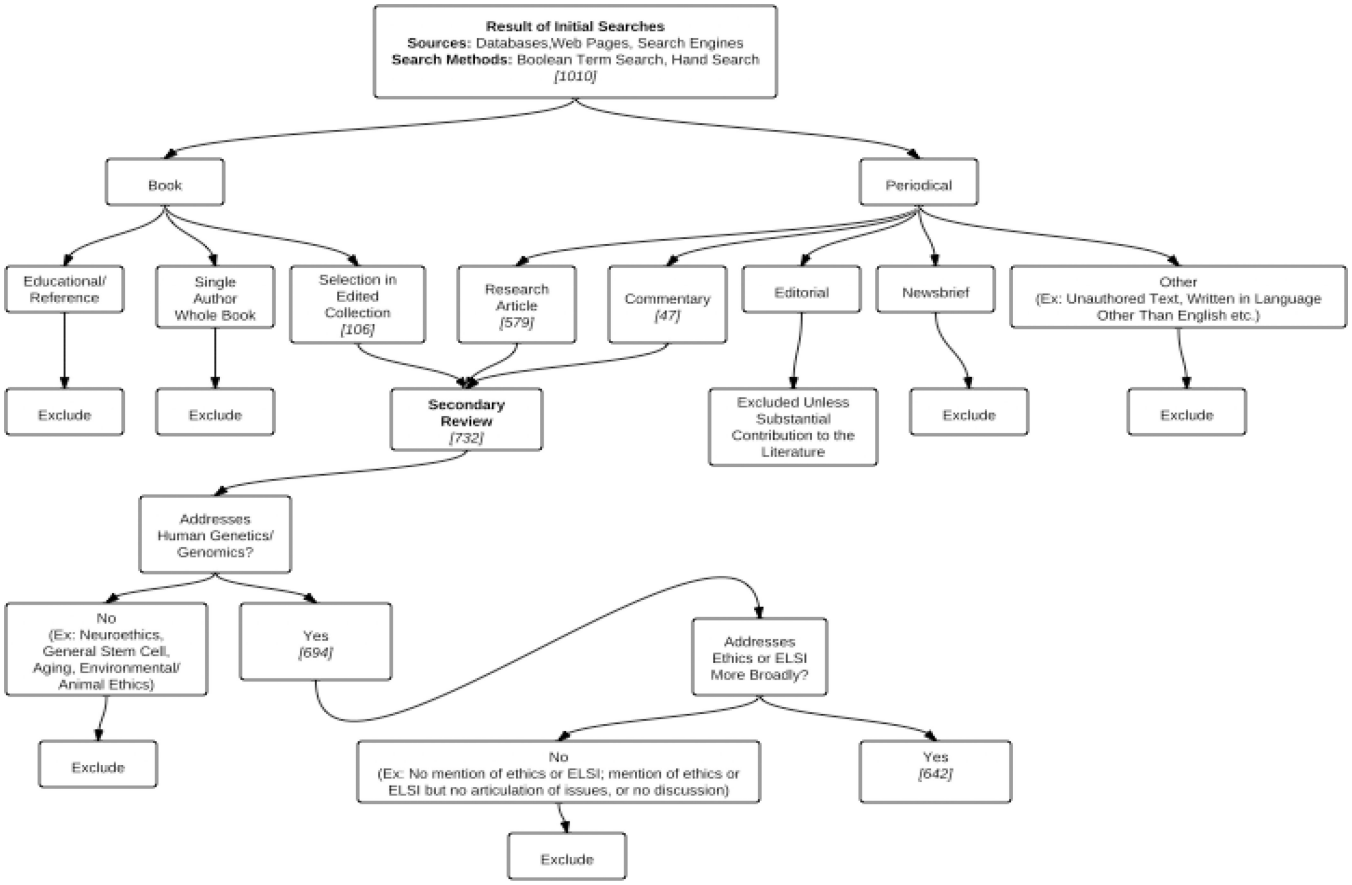

Figure 1.
Identification of Publications Used in this Study

Table 1

Reported Sources of Grant-based, Extramural, or Intramural Funding

	Number of Publications	Number of Publications that Reported Funding[1]	Mean # Reported Sources/ Publication[2]	Number of Publications that Reported (Some) Funding from the Specified Funding Mechanism[3]					
				NHGRI	Other US-Gov	Non-Us Gov	University	Non-Profit	Private
All Publications	**642**	**216 (34%)**	**.65**	**102 (16%)**	**39(6%)**	**59 (9%)**	**25 (4%)**	**36 (6%)**	**6 (1%)**
Methods									
Empirical	107	83 (78%)	1.49	53 (50%)	12 (11%)	13 (12%)	12 (11%)	15 (14%)	2 (2%)
Non-Empirical	535	133 (25%)	.49	49 (9%)	27 (5%)	46 (9%)	13 (2%)	21 (4%)	4 (1%)
Publication Forum									
Book Chapter	106	14 (13%)	.21	5 (5%)	3 (3%)	6 (6%)	1 (1%)	4 (4%)	0 (0%)
Bioethics Journal	188	66 (35%)	.60	25 (13%)	8 (4%)	25 (13%)	6 (3%)	12 (6%)	2 (1%)
Law Journal	23	5 (22%)	.30	2 (9%)	0 (0%)	1 (4%)	2 (9%)	1 (4%)	0 (0%)
Medical Journal	163	68 (42%)	.81	36 (22%)	17 (10%)	15 (9%)	8 (5%)	9 (6%)	4 (2%)
Public Health Journal	52	31 (60%)	1.46	18 (35%)	7 (13%)	4 (8%)	1 (2%)	6 (12%)	0 (0%)
Science Journal	63	15 (24%)	.52	6 (10%)	2 (3%)	5 (8%)	2 (3%)	1 (2%)	0 (0%)
Social Science or Humanities Journal	47	17 (36%)	.79	10 (21%)	2 (4%)	3 (6%)	5 (11%)	3 (6%)	0 (0%)

[1]The percentages reported in this column are the proportion of publications within a particular method or publication forum category (e.g. “non-empirical” or “book chapters”) that report at least one source of extra- or intramural grant based source of funding.

[2]The mean difference (with respect to number of acknowledged sources of funding) between publications adopting empirical and those adopting non-empirical methods is significant at the .05 level (.000). The mean differences (with respect to number of sources of funding per publication) between the following categories of publications are significant at the .05 level: Public Health Journal and Book Chapter (.000), Public Health Journal and Bioethics Journal (.002), Public Health Journal and Law Journal (.021), Public Health Journal and Science Journal (.008), and Medical Journal and Book Chapter (.013).

[3]The percentages reported in these columns are the proportion of publications within a particular method or publication forum category (e.g. “non-empirical” or “book chapters”) that report at least one source of extra- or intramural grant based funding from the agency or kind of agency listed. As these funding agencies are not mutually exclusive, and some publications reported multiple sources of funding, the percentages will not total the percentage indicated for the category in the “reported funding” column.

Table 2

Most Prevalent ELSI Topics[1] within Publication Forums and Reported Sources of Funding Categories

Reported Sources of Funding	Publication Forum
No Reported Sources of Funding (n=426)	*Book Chapter (n=106)*
• Genomics Generally (46; 11%)	• Genetic Enhancement (19; 18%)
• Genetic Enhancement (38; 9%)	• Genomics Generally (16; 15%)
At Least One Reported Source of Funding (n=216)	*Bioethics Journal (n=188)*
• Genomic Research and the Public (27; 13%)	• Biorepositories (19; 10%)
• Genetics and Race (22; 10%)	• Genomics Generally (19; 10%)
NHGRI (n=102)	*Law Journal (n=23)*
• Genomic Research and the Public (17; 17%)	• Genetic Enhancement (3; 13%)
• Genetics and Race (11; 11%)	
Other US-Government (n=39)	*Medical Journal (n=163)*
• Genetics and Race (6; 15%)	• Genomics and Clinical Practice (18; 11%)
• Biorepositories (5; 13%)	
Non-US Government (n=59)	*Public Health Journal (n=52)*
• Biorepositories (8; 14%)	• Genetics and Race (9; 17%)
• Genomic Research and the Public (8, 14%)	
University (n=25)	*Science Journal (n=63)*
• Genetics and Race (4; 16%)	• Biorepositories (10; 16%)
• Genomic Research and the Public (4; 16%)	• Intellectual Property (6; 10%)
Non-Profit (n=36)	*Social Science or Humanities Journal (n=47)*
• Informed Consent (5; 14%)	• Intellectual Property (6; 13%)
Private (n=6)	
• Each publication addressed a different topic	

[1]The topics reported here are presented in more detail in Walker and Morrissey (2012). Topics were developed using session headings from the 2008 ELSI Congress, and were modified to effectively capture the literature in our study. Two topics are listed under each funding or publication forum unless one specific topic was much more dominant than any other specific topic.