ETHICAL GENETIC RESEARCH
ON HUMAN SUBJECTS

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ABSTRACT: Since the Nuremberg trials and the Nazi doctors trial following World War II, international ethics protocols have emerged designed to protect human subjects from the atrocities of medical experimentation that were literally routine under the Nazis. Some of the apparent "lessons" from the Nazi period have been encapsulated in the Declaration of Helsinki, perhaps the leading medical ethics protocol. This paper argues that these protocols have not been notably conducive to human welfare or to the protection of human rights in the field of human genetics research. The paper proposes new protocols and a new approach to the ethics of research on human subjects.


Since the Nuremberg trials and the Nazi doctors' trial following World War II, international ethics protocols, designed to protect human subjects from the atrocities of medical experimentation that were literally routine under the Nazis, have emerged. Some of the apparent "lessons" from the Nazi period have been encapsulated in the Declaration of Helsinki, perhaps the leading medical ethics protocol. This paper argues that these protocols have not been notably conducive to human welfare or to the protection of human rights.

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The World Medical Association Declaration of Helsinki states that "[c]oncern for the interests of the subject must always prevail over the interests of science and society." Of course, if the interests of society referred to are the interests of the National Socialist Party in Germany in the 1930s, the principle seems plausible. However, the attempt to guard against the dangers of the Nazi party has produced poor, and even incoherent, ethics.

The Declaration of Helsinki has been used to veto scientific research that is not directly for the benefit of the participants or not specifically acknowledged by the participant to be in her very narrowly conceived interests. This has been particularly true in the context of research on new HIV/AIDS vaccines and therapies that are cheaper and more accessible to low income countries. Given this effect of the Declaration of Helsinki, it is important to assess the extent to which it offers either useful or even ethically defensible guidance in the context of genetic research. This paper examines the concept of "concern for the interests of the subject" and argues for a new principle that would be appropriate for genetics research.

I. MUST CONCERN FOR THE INTERESTS OF THE SUBJECT ALWAYS PREVAIL OVER THE INTERESTS OF SCIENCE AND SOCIETY?

The mere fact that a good society and a clearly unethical one share a feature does not necessarily show that they are equally unethical and, even if it were true that the Nazis did subordinate the interests of the individual to those of science and society, it would not follow that this was necessarily wrong. Thus it is appropriate to turn to the merits of the Declaration's claim that "concern for the interests of the subject" always outweighs "the interest of science and society." We should note at the outset that what is in an individual's interests is an objective matter. People often have self-harming preferences (such as smoking, drug abuse, selfless altruism), and they are sometimes bad judges of their

3. Id. at art. 1, para. 5.
4. Even narrowly interpreted, it is difficult to see how the Holocaust served genuine interests of anyone.
5. See John Harris, Research on Human Subjects, Exploitation and Global Principles of Ethics, in CURRENT LEGAL ISSUES 3: LAW AND MEDICINE (Andrew D.E. Lewis & Michael Freeman eds., forthcoming 1999). In this paper, I apply some of the arguments developed there to research into human genetics.
6. This paper is concerned with general principles appropriate to research ethics and does not attempt a detailed analysis of problems specific to genetics research. However, the arguments indicate the need for a change in our understanding of what is permissible in genetics research.
7. Arguing otherwise is like raising questions about the ethics of a rail system characterised by the punctuality of its trains and suggesting that such a system is wicked because the Nazis (allegedly) made the trains run on time. This is effectively the invocation of a principle definitively lampooned by F.M. Cornford in 1908. "The principle is that a few bad reasons for doing something neutralise all the good reasons for doing it." F.M. CORNFORD, MICROSOGMAGHIA ACADEMICA: A GUIDE FOR THE YOUNG ACADEMIC POLITICIAN ch. VIII (1908).
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interests. An individual’s preferences are not necessarily reliable indicators of his interests. Thus, the respect for persons that underpins this guideline has two clear, if sometimes incompatible, elements, namely, concern for welfare and respect for autonomy.

In evaluating what is in the best interests of another person, we must be wary of being too conservative about what benefits someone or of defining someone’s interests too narrowly. This is particularly the case when the very possibility of undertaking research is made to turn on this issue. How then should we understand the benefits of research to research subjects and to society? We all benefit from living in a society and in a world in which medical research is carried out and which utilises the benefits of past research. It is of benefit to patients and research subjects, as well in their interests, to be in a society that gives high priority to research and that pursues and actively accepts the benefits of research. We also benefit from the knowledge that there is ongoing research into diseases or conditions to which we may someday succumb. It makes us feel more secure and gives us hope for the future—for ourselves, our descendants, and others. To this extent, all well-founded research is of clear benefit to all people with access to suitable medical care. A narrow interpretation of the requirement that research be of immediate and direct benefit to the subject of the research is therefore perverse.

In addition, despite the implication in the Declaration of Helsinki, the interests of the subject cannot be paramount if this involves a judgement about the relative weight of the interests of research subjects compared to those of others. Being or becoming a research subject cannot conceivably augment one’s moral claims or, for that matter, one’s rights. All people are morally important; with respect to one another, each has a claim to equal consideration. To say that concern for the interests of the subject must prevail over those of others must be understood as asserting that a researcher’s narrowly conceived professional interests must not have primacy over the human rights of research subjects. But it is not plausible to claim that the research community, the health care system, society, or even the world community, should be more concerned about the rights or interests of research subjects than about those of other equally vulnerable people.

Perhaps the claim that concern for the interests of the subject must always prevail should be interpreted as a plea to privilege the rights or interests of a particularly vulnerable group in order to protect them from abuse. The idea here would be that to secure equal protection of rights and interests, enhanced respect would have to be accorded to particularly vulnerable individuals or groups to

8. However, they can never be bad judges of their wishes. Leaving aside the problematic case of unconscious wishes, humans may be truly said to have infallible awareness of their own preferences. We address the issue of autonomy below.

9. See, e.g., John Harris, The Ethics of Clinical Research with Cognitively Impaired Subjects, 18 ITALIAN J. NEUROLOGICAL SCI. 9 (1997); John Harris, The Principles of Medical Ethics and Medical Research, 15 CADERNOS DE SAUDE PUBLICA RIO DE JANEIRO 7 (Supp. 1 1999).
neutralise their vulnerability and secure the equality that their vulnerability threatens to undermine. But the claim that research subjects are especially vulnerable when compared to those who may suffer if research is not pursued is not plausible. For such a claim to be sustained, it would have to be established in particular cases. Certainly, it should not simply be accepted as a truism, especially when the consequences of doing so may prejudice other vulnerable individuals.

This is not to say that human rights are vulnerable to the interests of society. On the contrary, the rights and interests of research subjects are just the rights and interests of persons; they must be balanced against comparable rights and interests of other persons. In the case of medical research, the contrast is not between vulnerable individuals on the one hand, and an abstract entity like “society” on the other. Rather, it is between two different groups of vulnerable individuals. The rights and interests of research subjects are not served by privileging them at the expense of the rights and interests of those who will benefit from research. Both groups are potentially vulnerable. Neither is *prima facie* more vulnerable or deserving of special protection. Thus, the point is not that there is some general incoherence in the idea of sometimes privileging the rights and interests of particularly vulnerable groups. Rather, I am suggesting two things. First, that all people have equal rights and entitlement to equal consideration of interests. Second, any derogation from a principle so fundamental as equality must be justified by especially powerful considerations. What powerful considerations might justify privileging the interests of research subjects? To this we will now turn.

**II. LESSONS FROM HISTORY**

I have alluded already to dangers of superficial “lessons from history.” There is no space here for a historical essay on the lessons from the Nazi period,10 but it is important to note that “research subjects” did not constitute the vulnerable class under the Nazis. Rather, there was wholesale disregard for the value of life and for individual rights and liberties. It was this general contempt that made possible, among other atrocities, the Nazi medical experiments. While this disregard of the value of life was directed systematically at particular sections of the population, it was by no means confined to them, as the “night of the long knives” in June 1934, during which Hitler eliminated hundreds of his own followers, demonstrates.11

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11. As the historian Alan Bullock remarked of Hitler’s systematic elimination of rivals among his own followers, “[n]ever had Hitler made so patent his total indifference to any respect for law or humanity, and his determination to preserve his power at any cost.” ALAN BULLOCK, HITLER: A STUDY IN TYPANNY 308 (1962).
A similar point can be made about the “lessons” more recently drawn from the notorious Tuskegee Study of Untreated Syphilis. In that study, 412 poor African-American men were deliberately left untreated from 1932–1972 so that the natural history of syphilis could be determined. Even when penicillin became known to be effective against syphilis, they were left untreated. The principal ethical problem with the Tuskegee study was the complete absence of informed consent. Initially, the subjects were not informed that there were therapies available (which admittedly were not very effective). When penicillin became a highly effective and inexpensive treatment, they were not informed that their health was being compromised by omission of effective antibiotic therapy. Moreover, the subjects were told lies about the purposes of some of the procedures. For example, the spinal taps designed to monitor protein levels were described to the subjects as a new form of treatment. The subjects were deliberately denied the most basic information and the opportunity to consent or object to participation. Here, the problem and its lessons are complex. Any analysis would have to consider the attitudes toward poor black people that permitted the scientifically dubious study to be initiated and the systematic contempt shown to the rights and interests of the participants long after the purpose of the study (if there ever was one) had been overtaken by the development of effective treatments.

III. OBLIGATIONS TO AND OF RESEARCH SUBJECTS

What then should be the obligations of researchers to their subjects? Obligations to research subjects are derived from a more general obligation to refrain from harming others. Such obligations to research subjects are no more stringent than they are to anyone in similar need.

A. Sources of an Obligation to Participate in Research

Someone who benefits from research but refuses to participate in it is clearly acting unfairly by free-riding on the contribution of others. Where people volunteer to participate in research (at least where the risks and dangers to them are minimal), they are doing what any reasonable and decent person should be willing to do—both because of the overwhelming utility of the research and because they wish and expect to receive the benefits of research in their turn. The level of protection required to render the risks of participation minimal are then

14. The obligation of non-maleficence, which is the obverse of the obligation of beneficence, is generally acknowledged as one of the major principles of bioethics, if not of ethics more generally. See JOHN HARRIS, VIOLENCE AND RESPONSIBILITY (1980); TOM L. BEAUCHAMP & JAMES F. CHILDESS, PRINCIPLES OF BIOMEDICAL ETHICS (4th ed. 1994).
a question of fact or at least of judgement in each case. This suggests that where risks, dangers, or inconvenience of research is minimal, and the research is well-founded and likely to be for the benefit of oneself or others, there is some (perhaps very modest) moral obligation to participate. If this tentative conclusion is valid, it follows that those who decline to participate or refuse permission for their tissue samples to be used are acting wrongly.

I am not here invoking the principle developed by Herbert Hart and later used by John Rawls that is sometimes called the "principle of fairness." That principle may be interpreted as saying "those who have submitted to . . . restrictions have a right to similar acquiescence on the part of those who have benefited from their submission." I do not suggest any enforceable obligation to participate based on fairness. Neither do I propose any right possessed by those who participate to similar acquiescence on the part of those who benefit. The obligation to participate derives not from the unfairness of being a free rider, but from the importance of the research and the extent to which it is of both personal benefit and utility to the research subjects, future generations, and society in general. I merely note that being a free rider is unfair and that people always have a moral reason not to act unfairly. I suggest later that we should neither presume that people wish to act unfairly, nor should we institutionalise mechanisms that encourage this.

In sum, I have put forward four major points that bear on the participation of human subjects or the use of their tissues in genetic studies. First, both research subjects and those who might benefit from research are potentially vulnerable groups. Both have a claim to our concern, respect, and protection. Neither has an overriding claim. Second, all have an interest in the furtherance of research that is well-founded and of substantial therapeutic benefit. All decent citizens should, in principle, be willing to do their share to further such research where risks are minimal and expected benefits significant. Third, to fail to contribute to research is against the public interest and may harm others. Finally, it also is unfair to benefit from others' contribution to research without being willing to play one's own part.

If these conclusions seem startling or even dangerous, we should recall that there is sometimes a strong obligation to make even quite substantial sacrifices for the community. The community is sometimes entitled to deny autonomy and even violate bodily integrity in the public interest. This obligation is recognised in many ways, ranging from control of dangerous drugs, to control of road traffic, to compulsory vaccination, screening tests, and blood donations, to quarantine for dangerous communicable disease, to compulsory military service,

17. See John Harris, Ethical Issues in Geriatric Medicine, in BROCKLEHURST'S TEXTBOOK OF GERIATRIC MEDICINE AND GERONTOLOGY 1611–22 (R.C. Tallis et al. eds., 5th ed. 1998).
to detention under mental health acts, to safety guidelines for certain professional activities of HIV-positive people, to compulsory jury service. All of these involve some denial of autonomy and some imposition of public standards even where compliance is not based upon the competent consent of individuals. These cases may be exceptional, but they demonstrate that overriding moral considerations can take precedence over autonomy. This widespread and widely accepted practice of mandatory participation in “public goods” merits further discussion.

B. Mandatory Participation in Public Goods

Two familiar cases, jury service and coroner-ordered post-mortem examination (autopsy), illustrate the existence of a moral obligation to participate in “public goods.” All British citizens between 18 and 70 are liable for jury service. If called, they must appear, and unless excused by the court, they must serve. Such service can involve months of daily confinement in a jury box or room. Most people will never be called, but some must serve if the system of justice is to function. Participation in or facilitation of this public good is mandatory.

In most jurisdictions, the courts or the coroner can order a post-mortem examination. Despite the fact that autopsies involve interference with the dignity of a dead body and the removal of organs and other tissue, no consent is required. Of course post mortems are not ordered out of simple curiosity, but rather out of public safety and public policy considerations. It is important that the cause of death be known in case that cause presents a further danger to the community.

Participation in research involves features analogous to jury service or coroner-ordered post-mortem examination. All are important public goods for which citizens are called upon to make some sacrifice of autonomy and perhaps to undergo some inconvenience or sacrifice for the public good. This latter feature is particularly important. An example may help explain our attitude toward the imposition of risk in the public interest. Imagine an ocean liner transporting one thousand people on a cruise. The captain receives a radio message that another ship is in distress some miles to the north. Two hundred people are aboard the other ship, and the cruise liner is the only ship that can rescue them before the stricken ship will founder. The captain knows that if he diverts into the storm, he will impose some risk on his passengers and crew. There will be a small but significant risk of death for all. The storm is a bad one, but the modern liner should be able to cope. There is a greater, but still small, risk of death for a few of his passengers and crew in the rough and tumble of the rescue. Finally, because the storm is severe, a rescue effort almost certainly will subject his many elderly passengers to risk of minor injuries in the rough seas and

18. I use the term in a non-technical sense.
19. Those over age 65 may be excused if they wish.
20. For example, that danger may be in the form of a disease or contagion, or in the form of a possible murderer at large.
to discomfort, fear, and inconvenience. The captain knows he must attempt the rescue and subject his passengers and crew to the attendant risks. Few would disagree. He also knows that he can and must do so without asking for the consent of his passengers and crew, for they would be wrong to withhold their consent, and the captain would be wrong to permit refusal.\footnote{See, e.g., \textit{John Harris, Wonderwoman and Superman: The Ethics of Human Biotechnology} ch. 5 (1992).}

Of course, the existence of circumstances where an important public good licenses the suspension, or even the disregard, of fully informed consent is not a licence for wholesale disregard of consent. On the contrary, fully informed consent is the best guarantor of the interests of research subjects, and requiring consent expresses equal concern and respect for them as autonomous persons. However, cases like the ship in distress remind us that applying the principle of equality sometimes necessitates respecting the difference in force, urgency, and moral weight of competing claims.

If important public goods can justify conscription, then, \textit{a fortiori}, less Draconian measures to achieve that public good are justifiable. Medical research can be a public good of importance comparable to those which we standardly secure by coercion. However, to say that the use of a particular strategy such as coercion for achieving a goal would be justified is clearly not to say that its use is necessarily good policy. There are many things that we would be justified in doing that we nonetheless should not do. There are good policy reasons why coercion should be a last resort in a democracy. For example, a government might conclude that it would be morally justified in funding a particular public good by taxation. However, it might decide that a better policy would be to secure that good by voluntary contributions, if possible. Still, that the public good is sufficiently important to be secured by conscription (taxation in this case) may demonstrate the justifiability of incentives to secure the required voluntary contributions.

\textbf{IV. RESEARCH ON THE HUMAN TISSUE ARCHIVE}

An overwhelming case has been made for the utility and moral importance of research on the Human Tissue Archive.\footnote{See, e.g., \textit{David Korn, Contribution of the Human Tissue Archive to the Advancement of Medical Knowledge and the Public Health, A Report to the National Bioethics Advisory Commission} (Jan. 1, 1998).} The importance of the protection of genetic privacy also has been well rehearsed.\footnote{Bartha Knoppers et al., \textit{Control of DNA Samples and Information}, 50 GENOMICS 385 (1998).} These two important interests must be balanced. The key lies in understanding that genetic privacy is not a good in itself but a means to the protection of other goods. If genetic privacy is important, it is so because of the rights and interests that may be put at risk if it is compromised. These rights and interests need to be spelled out in detail so that they can be measured against the rights and interests that may be sacrificed if
genetic privacy is unconditionally respected. Such a task is beyond the purview of this paper. However, if I am right in thinking that well-founded genetic research is a public good, then a number of things follow.

It should not simply be assumed that people would not wish to act in the public interest, at least where the costs and risks involved are minimal. In the absence of specific evidence to the contrary, if any assumptions are to be made they should be that people are public-spirited and would wish to participate. Likewise, it may be presumed that people would not consent to do things contrary to their own and to the public interest.

If there is a general obligation to act in the public interest, then there is little reason to regard participation as actually or potentially exploitative and less reason to challenge consent. When people fulfill their moral and civic obligations, we do not usually ask “Are you quite sure you want to?” We do not usually insist on informed consent in such cases, but are usually content that they merely consent or simply acquiesce. When, for example, I am called for jury service, no one says, “only attend if you fully understand the risks and costs of being a juror and the benefits to the individual and to society.”

A. Me and My Kind

It is sometimes claimed that even where consent is problematic, as with genetic research on archival material from individuals who are dead or cannot be traced, the research may be legitimate if it is for the benefit of the health needs of the subjects or of people with similar or related disorders. Confining research that is not directly beneficial to the patient to that which will benefit the category of patients to which the subject belongs is untenable. What is the most appropriate reference group of sufferers from a particular disease? Surely any moral obligation I have to accept risk or harm for the benefit of others is not confined to those others who are narrowly like me. This is close to claiming that research should be confined to others who are “black like me” or “English like me” or “God-fearing like me.” The most appropriate category is surely “a person like me.”

B. The Demands of Ethics

Ethics cannot demand that we sacrifice the many who would benefit from research to the interests of the few who participate. Neither can it be ethical to do

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24. If these suggestions are broadly acceptable and an obligation to participate in research is established, this may well become one of the ways research is funded in the future.


26. I make a distinction between humans and persons that is not particularly pertinent in this context but explains my choice of terminology. See JOHN HARRIS, THE VALUE OF LIFE ch. 1 (1985); John Harris, The Concept of the Person and the Value of Life, KENNEDY INST. ETHICS J. (forthcoming 1999).
the reverse, namely, to sacrifice the participants in the trial to the needs of the many who wait upon its result. This paper contains no suggestion of such sacrifice of research subjects. To determine what is ethical, we must carefully and compassionately ascertain what it is reasonable to put to potential participants for their free and unfettered consideration or what it would have been reasonable for individuals who have previously provided tissue samples to have agreed to. If potential research subjects have full information and free choice, the only question is whether it is reasonable to permit them to participate, given the risks and likely gains. These gains include any benefits to them personally of participating in the study and any benefits that will flow to other persons who are equally entitled to concern, respect, and protection. Framing the question in this way reveals that the standards of care and levels of protection to be accorded to research subjects who have full information are somewhat study-relative.

C. Genetics Research

With respect to genetics research and particularly research on the human tissue archive, is it reasonable that people accept that stored tissue be available for medical research? If the donors of the archive tissue are dead, there is no question of the protection of research subjects for they (by hypothesis) cannot be harmed by the study. There is, of course, still the issue of whether their wishes with respect to the posthumous use of their tissue should be respected. The interest in having wishes satisfied that cover events after death is an instance of “persisting interests.” While such interests deserve some respect, they are relatively unimportant when compared with the interests of existing individuals who can be personally harmed by the neglect of those interests. Whether persisting interests of the dead should be respected is no different in principle from the question of whether their wishes as to the disposal of other parts of their estate should be respected. The appropriate principle is that their wishes should be respected subject to reasonable demands of public interest. This is the case with wills and other testamentary dispositions. The public interest is, after all, respected in the payment of death duties which usually are very much against the wishes and interests of the dead. Testing archival samples of deceased citizens might be regarded as analogous to taxing their estate to raise revenue.

Of course, the information gleaned from archival samples may be not only sensitive with respect to the sources of that tissue, but also for living relatives. Here it will be particularly important to ensure the security of test results and to

27. I discussed this special class of interests which may be said to survive death in HARRIS, supra note 21, at 100–01. Such interests also have been called “critical interests.” See RONALD DWORKIN, LIFE’S DOMINION 201–16 (1993).
28. HARRIS, supra note 21, at 100–01.
29. There is a lesson to be learned here from the case of cadaver organ donation. See HARRIS, supra note 26, at 219–23.
provide an effective system for anonymizing samples. Although these issues are important, they are matters of detail rather than of principle.

With living tissue providers, the only issue is whether it is more important to protect their autonomy than to carry out the research. This question is also probably study-specific. However, the argument of this paper is that we should not assume that the answer must always place individual autonomy above the present and future interests of others in the success of the research. Autonomy, as every taxpayer, juror, or military conscript knows, is not an inviolable right or interest.

D. The Requirements of Justice and the Missing Principle of Helsinki

It is crucial that the powerful moral reasons for conducting genetic research are not drowned by the powerful reasons for protecting research subjects. While there is a balance to be struck, it is not a balance that must always be loaded in favour of the protection of research subjects. To be sure, they are entitled to our concern, respect, and protection, but they are no more entitled to it than are those threatened by genetic diseases.

The Declaration of Helsinki has a missing article. Article 4 of the Declaration states that “[b]iomedical research involving human subjects cannot legitimately be carried out unless the importance of the objective is in proportion to the inherent risk to the subject.” The missing principle is the correlate of this:

Biomedical research involving human subjects cannot legitimately be neglected, and is therefore permissible, where the importance of the objective is great and the risks to and the possibility of exploitation of fully informed and consenting subjects is minimal. In the case of archival tissue where consent to its acquisition has already been given, further study is permissible under the same conditions of importance where anonymity and untraceability by third parties can be guaranteed.

Thus, while fully informed consent and the continuing provision of relevant information to research subjects does not eliminate all possibility of exploitation, it does reduce it to the point where it is no longer ethical to neglect the claims and the interests of those who may benefit from the research. Fully informed consent and the concern and respect for the individual that it signals sever all connection with the Nazi experiments and rebut spurious comparisons with the Tuskegee study. It is the recognition of the obligation to show equal

30. Declaration of Helsinki, at art. 4.
31. Where information gleaned from genetic testing may be important to those affected by it, there may be some duty to trace and inform all of those affected if reasonably possible. The detailed requirements of and constraints on such tracing are beyond the purview of this paper.
32. See Angell, supra note 12.
33. See id.; see also HASTINGS CENTRE REPORT, supra note 13.
concern and respect for all persons that is the defining characteristic of justice. The recognition that the obligation to do justice applies not only to research subjects, but also to those who will benefit from the research, constitutes an advance in thinking about international standards of research ethics.

V. INDUCEMENTS TO PARTICIPATE IN RESEARCH

Most research ethics protocols and guidelines are antipathetic to inducements. For example, the CIOMS guideline permits payment in cash or kind but states that if inducements are offered to subjects, "the payments should not be so large or the medical services so extensive as to induce prospective subjects to consent to participate in the research against their better judgement." This is described as "undue inducement." But the CIOMS document places a gloss on this guideline. It states that "[s]omeone without access to medical care may be unduly influenced to participate in research simply to receive such care." The nub of the problem is defining what makes inducement undue. If inducement is undue when it undermines "better judgement," then it cannot simply be the fact or level of the inducement that undermines better judgement. If this were so, all jobs with attractive remuneration would constitute "undue" interference with the liberties of subjects and anyone who uses his better judgement to decide whether a total remuneration package plus job was attractive would be unduly influenced. On the other hand, if no reasonable person would participate in the study without incentives to induce them to disregard their "better judgement," then undue influence would be present.

When genetics research is well-founded scientifically, has important objectives that will advance knowledge, and imposes minimal risk and non-onerous obligations on subjects, then surely it is not only in everyone's best interests that some people participate, but also in the interests of those who do. Better judgement will not indicate that any particular person should not participate. Of course, someone might not participate, objecting that it is too much trouble, not worth the effort, or rather inconvenient. However, incentives that remove the force of these sorts of objections no more undermine better judgement than do incentives that make employment attractive to potential employees.

34. See RONALD DWORKIN, TAKING RIGHTS SERIOUSLY (1977).
35. GENEVA: COUNCIL FOR INTERNATIONAL ORGANIZATIONS OF MEDICAL SCIENCES, supra note 25, at 18, guideline 4.
36. Id. at 18–19.
37. The CIOMS gloss on its own guideline creates a kind of Catch-22 that is surely unreasonable and unwarranted. Wherever the best proven diagnostic and therapeutic methods are guaranteed by a study in a context or for a population who would not normally expect to receive them, this guideline would be broken. CIOMS guideline 4 therefore surely contradicts and violates not only the Declaration of Helsinki but also its own guideline 14.
38. See, e.g., M. Wilkinson & A. Moore, Inducement in Research, 11 BIOETHICS 373, 373–90 (1997); Paul McNeill, Paying People to Participate in Research: Why Not?, 11 BIOETHICS 390, 390–97 (1997); HARRIS, supra note 21, at ch. 6 (discussing commercial exploitation).
Inducements may be undue in a different sense. If a drug addict were offered the drug of her choice to participate, or if subjects were blackmailed, we might regard the inducements as undue. However, the inducement is not undue because it is improper to offer incentives to participate, because participation is against the best interests of the subject, or because the inducements are irresistible. Rather, the type of incentive offered is illegitimate, against the public interest, or immoral in itself.

If I offer you a million dollars to do something that is good in itself, involves minimal risk and inconvenience, is in your interests, and will benefit mankind, my offer may be irresistible, yet not coercive. In contrast, to threaten you with torture would be coercive even if you were going to do it anyway. Although I should be punished for my threat, blackmail, or criminal offer of illegal substances, your freedom to do the act should not be curtailed because of my wrongdoing. The wrong lies not in the fact that I attempted to force your hand, but rather in the methods that I chose. This is the distinction between "undue inducement" and "inducements that are undue." "Undue inducement" is the offering of inducements when none should be offered. This is what is referred to in the various international protocols. "Inducements that are undue" refers to the nature of the inducement, not to the fact of inducements of some sorts (even irresistible sorts) being offered. In light of this important but much neglected distinction, we can see that offering incentives, perhaps in the form of tax concessions to people to make archival samples available for research, would be ethical.

V. GENETIC PRIVACY

One objection to the use of human tissue archives that may be resistant to public interest arguments is the claim that there is a right to "genetic privacy." Rights to genetic privacy and genetic identity are often asserted by amateurs of popular science who lack awareness of the incoherence and mutual incompatibility of these alleged rights. Genetic privacy has to do with the privacy or secrecy of genetic information. Genetic identity is often confused with genetic uniqueness (the right to an exclusive genome). Genetic uniqueness cannot be a fundamental or basic human right because of the frequency with which it is violated without any harmful effects by the existence of monozygotic twins. Genetic identity, as opposed to genetic uniqueness, has to do with the extent to which our genes are shared with others. To put it crudely perhaps, the Hapsburg nose has to do with genetic identity, but is essentially public. It is therefore unclear how information about such genetic features could be the subject of privacy rights any more than could the identity of one's progenitors. Moreover, as Lee Silver brilliantly demonstrates:

[A] comparison between any two people in the world would show that, on average, they were 99.9% the same in their genetic information. Indeed, any two random people would be absolutely identical to each other at the vast majority of all their genes. . . . [W]ith over 6 billion people on the planet earth, it is
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extremely unlikely that any individual carries even a single unique allele of any
gene. Every allele that you have is also carried by other people.\(^{39}\)

Thus, it is unlikely that there could be a right to genetic privacy that implies
secrecy about one’s genes or genome. Of course, any right to privacy of medical
information would include privacy of information about genes that are indicative
of medical conditions so far as this “privacy” could reasonably be maintained.

The crucial “genetic privacy” issues are not really about privacy of
information—they are about abuse of information. Genetic privacy is in the most
important sense a lost cause. Genetic information is easily obtained, from direct
observation, from leaky medical data storage systems, or from surreptitiously
obtained samples of DNA such as saliva on a drinking glass. The best way to
protect the interests that might be served by concern for genetic privacy would
be to deter unreasonable, unfair, or perhaps unauthorised use of such
information.\(^{40}\)

VII. SPECIAL VULNERABILITY AND
SPECIFIC CONSENT

It is sometimes said that there are peculiarly vulnerable groups who have
special sensitivities to genetic research. These may include groups identified by
racial or ethnic affiliations, skin colour, or cultural history. These concerns are
legitimate in proportion to the illegitimacy of the research. This paper has
addressed the obligation to participate in well-founded research, which must be
both in the personal interest of research subjects and in the public interest.
Personal and public interest also include the protection of minorities from
discrimination and other consequences so damaging as to discredit the research
enterprise. What these might be is a matter for argument and debate. Clearly, all
defensible research will have to pass what Americans tend to call Institutional
Review Boards and English-speaking Europeans call Research Ethics Commit-
tees. This paper is concerned with the principles that should govern participation
in research that is well-founded and in both the personal interest of research
subjects and in the public interest.

A final issue concerns whether specific consent, as opposed to general
consent, is required for research on a human tissue archive. In the case of living
tissue donors, if consent is to be meaningful, it must be specific. However the
presumption should be that people would wish to consent to legitimate, well-
found research in the public interest where there is minimal risk to research
subjects. In the case of dead donors, because there is no risk, and, theoretically,
minimal prejudice of interests, consent should not be required.

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\(^{40}\) Discussion of what might constitute unreasonable, unfair, or unauthorised use of genetic
information is beyond the purview of this paper.
There is no justification for confining the definition of the interests of the research subject narrowly to include only personal and selfish interests. All people, including research subjects, have a substantial and real interest in ongoing medical research. Becoming a research subject does not augment anyone's rights or moral claims. Therefore, the interests of the research subject cannot be paramount. All individuals are entitled to be treated with equal concern and respect.

Adequate informed consent remains the best guarantor of the interests of living research subjects. While informed consent is not foolproof, residual dangers must be balanced against the benefits of conducting research. Fully informed consent and ongoing provision to research subjects of all relevant information distinguishes ethical research from the concerns of Nuremberg and the taint of Tuskegee. As with post-mortem examinations, however, consent of dead sources of human tissue or their relatives should not be required. In obtaining consent, the provision of ethical and legal inducements to research subjects is neither coercive nor otherwise unethical nor inappropriate as long as the research is well-founded and in the public interest.

Research on the human tissue archive clearly involves no physical risk to the sources of archive material. However, risks to rights and interests that flow from abuse of information can be extreme and must be protected to a degree commensurate with the probable gains from use of the archive. Security and effective punishment for wrongful use of genetic information are means to this end, as is protection against the wrongful use by employers, insurance companies, or government agencies of genetic information acquired without the consent of the individuals concerned.