Published in final edited form as:
*JAMA*. 2009 July 1; 302(1): 67–72. doi:10.1001/jama.2009.931.

# The Obligation to Participate in Biomedical Research

**G. Owen Schaefer, B.A.**, **Ezekiel J. Emanuel, M.D. Ph. D**, and **Alan Wertheimer, Ph. D**
Department of Bioethics, The Clinical Center, National Institutes of Health, Bethesda, Maryland, USA

## Abstract

The prevailing view is that participation in biomedical research is above and beyond the call of duty. While some commentators have offered reasons against this, we propose a novel public goods argument for an obligation to participate in biomedical research. Biomedical knowledge is a public good, available to any individual even if that individual does not contribute to it. Participation in research is a critical way to support that important public good. Consequently, we all have a duty to participate. The current social norm is that people participate only if they have a good reason to do so. The public goods argument implies that people should participate unless they have a good reason *not* to. Such a shift would be of great aid to the progress of biomedical research, eventually making our society significantly healthier and longer-lived.

## Introduction

John has a chronic condition for which there is a partially effective standard treatment. His physician tells him of a study testing a new therapy. Physicians are uncertain whether the new therapy improves upon the standard treatment. Participation requires John be randomized to either the standard or experimental treatment as well as receive extra blood draws and MRI scans.

Should John enroll in the study? Does he have a duty to enroll? On the standard view, John's participation is above and beyond the call of duty. It would be good of him to participate, but not wrong of him to refuse. On the *obligation view*, John has a moral duty to participate. Assuming that the burdens and risks of participation are not excessive, it would be wrong to refuse to participate.

We defend the obligation view. We do so not to make a philosophical point, but to stimulate support for a major cultural shift in the way physicians, researchers, patients, and society at large think about participation in research.

## The Standard View

According to the standard view, participation in research is akin to giving blood or donating to charity. [1–5] Participation that benefits society is supererogatory – while participants who put themselves at risk or inconvenience deserve praise, people who refuse to participate in research are not acting wrongly or unethically.

Correspondence to: Alan Wertheimer, Department of Bioethics, The Clinical Center, National Institutes of Health, Bethesda, MD 20892-1156, USA; 301-435-8729 (main line), 301-496-0760 (fax); wertheimera@cc.nih.gov.



Conflict of Interest Statement
We declare that we have no conflict of interest.

## Is There an Obligation to Participate in Research?

Although the standard view dominates current thinking, commentators have proposed two arguments for the obligation view: beneficence and free riding.

### Beneficence

According to the beneficence argument, if a person can prevent something bad or produce some good then that person has a duty to perform that action.[6–8] Any action that is beneficial to society overall would be obligatory. Participation in many clinical trials is therefore obligatory merely because it helps society at large.

It is certainly good to be beneficent, but the beneficence argument is excessively demanding as a basis for an obligation to participate in research.[9] It implies not only that people have an obligation to participate in research, but also to perform numerous acts which we normally consider supererogatory and to donate a large portion of their wealth for the sake of nobler causes. Indeed, participation would be morally obligatory even if there were a significant risk of harm so long as the expected societal benefit was sufficiently great. This argument is in our view unreasonably demanding.

In addition, if we accept a weaker version of the beneficence argument in which people have an obligation to perform a limited number of beneficent acts, the beneficence argument would not explain why one has a special obligation to participate in biomedical research as contrasted with other beneficent acts such as donating to charity.[10]

### Free Riding

According to another argument, the failure to participate in research is a form of free-riding.[6, 11–14] Free-riding occurs when a person receives a benefit that others pay for and takes advantage of the contributors by refusing to share the burden of obtaining it. An example is the speed hump: Frederick's neighborhood has a problem with speeders, and all the residents agree that a speed hump would make everyone much safer. Their municipality will allow the hump to be built only if the residents of the street pay for it themselves. The cost of Frederick helping the neighborhood pay for the hump is worth the hump's benefit to him, but he knows his neighbors want the hump so much that they will pay for it even if he does not contribute. Surely he should help pay.

The free-riding argument claims that people benefit from biomedical research. Usually they actively seek out the benefits, consuming safer, more effective medical treatments. Sometimes they benefit passively, as exemplified by herd immunity due to vaccination. By refusing to participate in biomedical research but accepting these benefits, people are free-riding on the people who participate.

Although this free-riding argument appears attractive, it fails for participation in research. The burdens of participating in biomedical research that current participants assume are not alleviated when people like John participate.[4, 5] Implicit in the free-riding argument is the claim that doing one's fair share will relieve others of the burdens of participation. Although this is true for the speed hump, it is not true with respect to biomedical research. John would not be paying back any *actual participants* – he is benefitting someone who will in fact not participate. Unlike the free-riding case, more participation helps society at large and future generations, but does nothing to relieve the burdens on people who are actually participating in research.

## Participating in Research Contributes To a Public Good

People have an obligation to participate in biomedical research because the knowledge produced by the system of biomedical research is what economists call a "public good."

A public good has two characteristics: First, one person's use of that good does not diminish another's use of that good; and second, it is impractical to prevent people from using the good.[15–17] Conversely, a good is private if one person's use does diminish another's use or if it is feasible to provide it to some people but withhold it from others. Typical examples of public goods are national security, a fireworks display, street cleaning, and clean air.[18] One citizen's benefit from a fireworks display or national security does not diminish another's benefit and a person cannot be prevented from benefitting from a fireworks display or national security even if he or she does not contribute to its provision. W*ho* provides the good is irrelevant to whether it is public or private. A private company might provide a public good like fireworks, while a government could provide unemployment benefits, which is a private good because it can be given to unemployed individuals but not to others.

There is a crucial difficulty in generating public goods. Normally, there is no incentive for any individual to contribute to a public good even if the benefit of that public good to the individual is greater than the cost of contribution.[16] No individual can be denied the benefit of a public good no matter how much or how little he has contributed himself. For that reason, public goods tend to be under-supplied.[19] To overcome this problem, society sometimes compels people to contribute: For instance, society mandates that cars come equipped with catalytic converters in order to provide the public good of clean air. In other cases, society gives people positive incentives to contribute, such as subsidizing administration of the flu vaccine to provide the public good of herd immunity. In still other cases, people contribute because they believe they have an obligation to do so. Many people vote not because they think that their vote will make a difference to an election's particular outcome but because they believe they have an obligation to support the public good of electoral democracy.[20, 21]

Biomedical research is devoted to generating a public good -- generalizeable biomedical knowledge.[22] Assuming that the knowledge is made public, one person's use of that knowledge does not deprive others of using it. Moreover, the benefit of that knowledge cannot be withheld from the public. The benefits of medical research to the public over the past century have been both significant and public, from the eradication of smallpox and near-eradication of polio to the development of penicillin, modern surgical techniques, and other life-saving discoveries. In addition to developing new interventions, biomedical research produces very important public knowledge of conditions and already-available treatments, as exemplified by research demonstrating that a lumpectomy is often just as effective as mastectomy in the treatment of breast cancer.[23, 24]

Clinical investigators, research institutions, and funding agencies were indispensible to these advances – but so too were the millions of people who agreed to be participants in the research which proved the effectiveness of the interventions that worked and, no less importantly, the ineffectiveness of those that did not.

Because the enterprise of biomedical research produces the important benefit of medical knowledge that is an advantage to us all, we all have an obligation to support that system of knowledge generation by participating in biomedical research. If it turned out that biomedical research with human subjects was not that important after all – that society would not be much worse off if all research on humans were to cease – then there would be no obligation to participate. But barring convincing evidence that such research is in fact unimportant, there is a duty to participate in research.

### Free riding vs. public goods

Although the classic free riding argument and the public goods argument both appeal to a duty to do one's fair share, there are crucial differences between them. First the public goods argument *aids the cause*, instead of merely *splitting the bill*. For example, suppose the catalytic converter on Daniel's car has deteriorated. Daniel has benefitted greatly from the reduction in pollution produced by catalytic converters. Should he replace his converter? The free riding argument is inapplicable here because replacing the converter would not ease the burden of pollution control on others. But according to the public goods argument, he should do his part in contributing to the public good of pollution control.

Second, a free-rider obligation requires relief for *people currently contributing*. By comparison, discharging a public goods obligation makes *society better off in the future*. This is why the public goods argument applies in John's case while the classic free-rider argument does not. John's participation helps supply present and future generations with important medical knowledge while not necessarily reducing the burden on those participants who made the knowledge available to him.

### Nature of the obligation

The obligation to participate in research is not absolute. Rather, people have what philosophers call a *prima facie* obligation to participate.[25] In other words, there may be circumstances or reasons that override or mitigate the force of the duty. For example, a parent may permissibly break a promise to meet a friend in order to care for his sick child. Similarly, if participating in a trial requires John to violate a sincere religious belief about bodily integrity or is excessively burdensome, then John's obligation to participate in research has been overridden and he is not morally required to participate.

It is difficult to specify the strength of the obligation to participate in research with any precision. Is it more important to spend a few hours with one's family or participate in research? Does the obligation hold if you live quite far from the research center? As with most theories of obligation, there is no mathematical algorithm. Tensions between obligations are an inevitable feature of our moral lives.[26, 27] This does not undermine or negate the obligation, but only highlights the complexity of ethical decisions. Nonetheless, the obligation has force. The obligation means that we *start* from the assumption that John ought to participate in the study. If he were to refuse, John should have a good reason for doing so.

How much is John required to do? John has an obligation to do his "fair share" of participation.[9] He is not required to enter every trial for which he eligible. By analogy, how often must an academic agree to review manuscripts for journals? Given that scholars benefit from the peer review system, they have a *prima facie* obligation to do their fair share of reviewing when asked. Yet they need not accept every request. Although there is no formula to determine how often one must accept such requests, or what factors can legitimately override the obligation, such moral uncertainty does not undermine the claim that academics have such an obligation. Similar uncertainty should not undermine the claim that everyone has a duty to participate in biomedical research.

## Implications of the Obligation to Participate in Research

### Enforcement

To say that John has a *moral* obligation to participate in a clinical trial does not mean that John should be *legally* compelled to do so. It is perfectly coherent to argue that there is a duty to vote but that people should not be compelled to do so, and no nation enforces an obligation to keep promises to friends even though most people think that one has an obligation to do so.

Legal coercion may be a legitimate tool in certain circumstances, such as paying taxes for defense or making cars with catalytic converters, but it is not so for biomedical research. There are sound moral reasons for thinking that a person should be able to decide what happens to his body even if he decides not to do what he is morally obligated to do, the kind of right to privacy inferred from the U.S. constitution[28, 29] and explicit in the European Convention on Human Rights.[30] A person's right over his body can justly be overridden in some circumstances, such as when society compels people to take a vaccine. But the need for biomedical research today does not qualify as such an extraordinary circumstance. We should also be wary of broader societal implications of compulsory participation.

An obligation to participate in biomedical research would also not alter the requirements of informed consent. If Robert has loaned tools to Samantha on many occasions, we might say that Samantha has an obligation of reciprocity to loan her tools to Robert when asked. Nonetheless, it would still be wrong for Robert to take Samantha's tools without Samantha's consent. Similarly, although one may have an obligation to participate in research, we can and should still insist that the participant give informed consent to do so.

The obligation to participate in research does not undermine the right to withdraw from participation in a trial.[31] To say that subjects have a right to withdraw is *not* to say that they have no prima facie obligation to remain in a study. It is to say that they should not be penalized for withdrawing even if withdrawal is wrong. And we are not proposing that subjects ever be penalized for withdrawal.

## Personal obligation

Individuals ought to participate in clinical trials when presented with the option. Well-functioning IRBs ensure that the risks are not going to be excessive relative to the benefits of research. When the risks are significant, the obligation may be weaker.

The obligation to participate applies to both healthy volunteers and patients. Both are needed to advance biomedical knowledge. For patients, there is an obligation to agree to participate in a study involving their condition when appropriate. Healthy individuals should participate in a fair share of the research for which they are eligible and needed.

## Cultural change

Just as many claim that citizens have an obligation to vote even though they are not legally required to do so, society should come to recognize that everyone has an obligation to participate in research when it is not excessively burdensome to do so. The current default position is "you don't have to participate in research if you don't want to." Instead, the default should be: "you should participate unless you have good reasons not to." We advocate a cultural and moral change, not a legal one.

One strategy to affirm and reinforce the belief that people have an obligation to participate in research would be a publicity campaign analogous to get-out-the-vote efforts which have helped convince 90% of Americans that there is a duty to vote.[21] The language of current advertisements could change from calling participants "everyday heroes" – implying participating is supererogatory – to using language similar to recycling ads: "do your part," or "it's your turn to participate."

Another strategy operates at the individual level. Researchers could use moral encouragement when attempting to recruit participants instead of emphasizing benefits to the individual as reasons to join studies.[32, 33] Additionally, physicians should be more willing to actively recruit patients onto important clinical trials.[34] Such encouragement would have to be given carefully; there is a risk that the participants would fear abandonment by their physician if they refused

to participate. In the very least, researchers can legitimately inform patients about how important biomedical research has been and will be to everyone's well being.

### Paying Others to Participate in one's Stead

In theory, the obligation to participate could be fulfilled by paying someone else to participate. Most U.K. and U.S. citizens discharge their obligation to defend their country by paying for an all-volunteer army through taxes. In principle, we could pay research participants enough so that no one would have to be asked to make any sacrifice by participation. But there are practical and moral limitations to this strategy. It would be in inordinately expensive to increase payment to research subjects enough to attract the millions of participants who are needed above current levels. In addition, we must be concerned about undue inducements. Offering someone enough to participate when that person would otherwise prefer not to might lead that person to misunderstand the burdens and risks of participation. Additional concerns over exploitation and data reliability emerge if participation is done abroad for the sake of speed and budget savings.[35] But if we are reluctant to pay people to participate abroad, we will have to put in more effort ourselves and be willing to participate ourselves. Given these limitations, the obligation to participate is often best discharged by personal participation.

## Objections Considered

The public goods argument is admittedly a minority position, and advocates of the standard view are likely to raise several objections which we will briefly address.

### Alternate contribution

Certain individuals can discharge their obligation to participate by contributing financially to other public goods, or societal goods in general. Instead of participating in research, a person could donate to Oxfam or the Special Olympics.[10]

It is practically infeasible to attempt a moral "accounting," where someone weighs the good deeds he or she has recently done to see if they are sufficient. And even if such were possible, it is problematic to have contributions in one sphere of action offset duties to contribute to other spheres. For example, a person's duty to recycle does not go away even if he has donated vast sums of money to charity. Similarly, participation in biomedical research is a separate sphere of activity from charitable contributions. Aiding in the sphere of charitable donations, then, would not be a way to offset one's obligation to assist the sphere of biomedical research through participation.

### Current contribution

The obligation to support biomedical research is fulfilled by paying taxes that support research at the NIH or MRC, paying drug prices and buying health insurance.[36, 37]

Biomedical research needs participants as well as financial support.[38] There are too few participants and adding more funding will probably not solve that problem. A shortfall of participants in biomedical research slows the completion of clinical trials more than lack of funding.[39, 40] By one estimate, if the proportion cancer patients that agree to participate in clinical trials were to increase from its current five percent to 10 percent, the usual study completion rate would decrease from around four years to one year.[41] Another estimate suggests that at least 16 million more people are needed to participate in research trials each year.[42]

The obligation to support research is preserved even if one has paid for insurance, purchased drugs, etc. Our situation is in some ways analogous to a wartime call to arms – not just money but soldiers to actually fight are needed.

### Equity

Wealthy people receive more benefits from biomedical research than poorer people; they are more able to afford new, expensive drugs and interventions. A poorer person does not have an obligation to support an institution that primarily benefits the wealthy.[43, 44]

The public goods argument maintains that an individual has an obligation to participate in research only if the burden of participation is less than that overall benefit of biomedical research to the individual. It is an open empirical question whether or not wealthy people ultimately get more benefit out of biomedical research than poorer people, but it is likely that the benefit from research to the poor exceeds the burden of participation for the poor as well. There is some evidence that while poor populations lag behind in health improvements compared to the wealthy, the poor populations often manage to catch up as interventions become cheap and widely available.[45] This is partially because medical knowledge is a public good; wealthy people's access to medical knowledge does not preclude poorer people from having access to it. Even if delayed, poorer people still receive benefits from interventions originally targeted at the wealthy. Access to a tuberculosis vaccine or AZT, for example, may be delayed for the less affluent, but they eventually get access and ultimately a greater improvement in their lives from the research since less affluent people are more threatened by diseases such as tuberculosis and HIV/AIDS.

### Excessive burden on the sick

Because much research can be conducted only with those with a particular disease or condition the obligation to participate in biomedical research falls disproportionately on sick individuals who already suffered enough. An obligation for the sick to participate in trials is unreasonably demanding.[5]

While it is unfortunate that the sick bear a disproportionate burden of participation in research, it is not unfair. It is an unavoidable fact of life that some obligations fall on some people and not others. It is not unfair that a witness to a crime has an obligation to report it and testify in court, whereas people who happen not to be witnesses have no such obligation. People sometimes acquire obligations simply because of the circumstances in which they find themselves by accident.

### Patent protection

Three-quarters of all biomedical research is actually sponsored by pharmaceutical companies.[41] While there may be an obligation to participate in publically-funded research, patented biomedical knowledge is not a public good. Hence, participation in industry-sponsored research which may produce patented knowledge is not an obligation.

Patents expire. Statins like Lipitor, for example, will soon be widely available at generic prices.

Moreover, a patent protects the production of a drug or device, but the knowledge of its effects is the public good. That knowledge is a core value of biomedical research, and it is the result of public and private research alike. Indeed, a private company can provide a public good. What matters is that the good is available to everyone, not that a public institution provide it. Consequently, we can have obligations to help private companies produce public goods. By analogy, someone might support the public good of national defense by working in a privately company producing bullet-proof vests instead of in a more lucrative profession. In the case of

biomedical research, private companies even have an incentive to spread the knowledge of a drug or device effectiveness to physicians since that is an effective way to get physicians to recommend those interventions. Whether a study is publically or privately financed has little bearing in itself on the obligation to participate in that study.

### Unsuccessful research

Much research benefits no one. Only a small percent of drugs tested will ever make it to market. Negative results are often not even published. Given the small chance any particular research study has to generate an effective intervention, the obligation would seem to be very weak.[41]

A negative result that is unpublished and unreleased is not a public good. That is a good reason to encourage the dissemination of the results of all studies. However, negative results which are disseminated to the medical community are indeed a public good. Knowing what does not work can be useful in itself and can contribute to other studies.

Even if many studies would not in hindsight be worth the effort, it only matters that the benefits of the research are expected to be worthwhile before the research is completed. Given that the research enterprise overall produces valuable public goods, and IRBs have determined that any particular research study has overall positive expected social value, the obligation remains in force. As Henry Beecher famously said, “An experiment is ethical or not at its inception; it does not become ethical *post hoc*.”[46] The same can be said of obligations – we should evaluate the importance of our contributions from an *ex ante* perspective.

## Conclusion

There is a *prima facie* obligation to participate in biomedical research. This obligation arises because biomedical research produces the public good of biomedical knowledge - a good which everyone has access to and which retains its value no matter how many people have access to it. The results of research do not just help the rich or powerful – all of us take advantage of this public good when we receive vaccines, take drugs, use medical devices, and the like. Many of us owe our entire lives to the biomedical knowledge which could only be produced with the contribution of many willing participants. The obligation to participate in biomedical research, then, makes reasonable demands on all of us. Participating in research is much less burdensome than contributing to many other public goods; joining the army is certainly more risky and time-consuming than *any* clinical trial which has been approved by a well functioning IRB. Indeed, paying taxes may be much more burdensome than participating in many research trials.

This is not to suggest that people have an obligation to become full-time guinea pigs. Instead, there needs to be a cultural shift in the moral framework that we bring to participation in research. The standard view of research participation must be changed from one in which participation is supererogatory to one in which people need to give a good reason *not* to participate. The shift is from participation in biomedical research being, like charity, above the call of duty, to such participation being a moral obligation for everyone to do his part.

## Acknowledgements

We thank Nathan Cherny, Frank Miller, Joe Millum and Seema Shah for helpful suggestions. This research was supported in part by the Intramural Research Program of the NIH, Clinical Center.

## References

1. Tait AR, Voepel-Lewis T, Siewert M, Malviya S. Factors that influence parents' decisions to consent to their child's participation in clinical anesthesia research. Anesthesia Analg 1998;86:50–53.

2. Madsen SM, Holm S, Davidsen B, Munkholm P, Schlichting P, Riis P. Ethical aspects of clinical trials: the attitudes of participants in two non-cancer trials. J Intern Med 2008;248(6):463–474. [PubMed: 11155139]
3. Barnbaum DR. Supererogation in clinical research. Med Health Care and Philos 2008;11:343–349. [PubMed: 18293099]
4. Heyd, D. Experimentation on trial: why should one take part in medical research?. In: Emanuel, E.; Crouch, R.; Arras, J.; Moreno, J.; Grady, C., editors. Ethical and regulatory aspects of clinical research: readings and commentary. Baltimore and London: The Johns Hopkins University Press; 2003. p. 161-166.
5. Jonas, H. Philosophical reflections on experimenting with human subjects. In: Emanuel, E.; Crouch, R.; Arras, J.; Moreno, J.; Grady, C., editors. Ethical and regulatory aspects of clinical research: readings and commentary. Baltimore and London: The Johns Hopkins University Press; 2003. p. 155-161.
6. Harris J. Scientific research is a moral duty. J Med Ethics 2005;31:242–248. [PubMed: 15800367] 2005
7. Herrera CD. Universal compulsory service in medical research. Theor Med 2003;24:215–231.
8. Rhodes R. In defense of the duty to participate in biomedical research. Am J Bioeth 2008;8(10):37–38. [PubMed: 19003705]
9. Murphy, L. Moral Demands in Nonideal Theory. Oxford: Oxford University Press; 2000.
10. Wachbroit R, Wasserman D. Research participation: Are we subject to a duty? Am J Bioeth 2005;5 (1):48–49. [PubMed: 16036661]
11. Caplan A. Is there a duty to serve as a subject in biomedical research? IRB 1984;6(5):1–5. [PubMed: 11650662]
12. Rhodes R. Rethinking research ethics. Am J Bioeth 2005;5(1):7–28. [PubMed: 16036651]
13. Evans HM. Should patients be allowed to veto their participation in clinical research? J Med Ethics 2004;30:198–203. [PubMed: 15082818]
14. Orentlicher D. Making research a requirement of treatment: why we should sometimes let doctors pressure patients to participate in research. Hastings Cent Rep 2005;35(5):20–28. [PubMed: 16295261]
15. Woodward, D.; Smith, RD. Global Public Goods and Health: Concepts and Issues. In: Smith, R.; Beaglehole, R.; Woodward, D.; Drager, N., editors. Global Public Goods for Health: Health Economic and Public Health Perspectives. Oxford: Oxford University Press; 2003. p. 3-32.
16. Olson, M. The Logic of Collective Action. Cambridge, MA: Harvard University Press; 1965.
17. Cornes, R.; Sandler, T. The Theory of Externalities, Public Goods and Club Goods. New York: Cambridge University Press; 1996.
18. Head JG, Shoup CS. Public Goods, Private Goods, and Ambiguous Goods. The Economic Journal 1969;79(315):567–572.
19. Samuelson PA. Diagrammatic exposition of a theory of public expenditure. The Review of Economics and Statistics 1955;37(4):350–356.
20. Wertheimer, A. In defense of compulsory voting. In: Pennock, JR.; Chapman, J., editors. Participation in Politics. New York: Lieber-Atherton; 1975.
21. Pew Research Center for the People & the Press Voter Attitudes Survey. [Accessed 3/13/09]. 2008 Junhttp://people-press.org/questions/?qid=1710357&pid=51&ccid=51#top
22. Ghosh, J. Medical Knowledge. In: Smith, R.; Beaglehole, R.; Woodward, D.; Drager, N., editors. Global Public Goods for Health: Health Economic and Public Health perspectives. Oxford: Oxford University Press; 2003. p. 119-136.
23. Veronesi U, Cascinelli N, Mariani L, et al. Twenty-Year Follow-up of a Randomized Study Comparing Breast-Conserving Surgery with Radical Mastectomy for Early Breast Cancer. N Engl J Med 2002;347(16):1227–1232. [PubMed: 12393819]
24. Fisher B, Anderson S, Bryant J, et al. Twenty-Year Follow-up of a Randomized Trial Comparing Total Mastectomy, Lumpectomy, and Lumpectomy plus Irradiation for the Treatment of Invasive Breast Cancer. N Engl J Med 2002;347(16):1233–1241. [PubMed: 12393820]
25. Ross, WD. The Right and the Good. Oxford: Clarendon Press; 2002.
26. Frankena, WK. Thinking About Morality. Ann Arbor: University of Michigan Press; 1980.

27. Lemmon EJ. Moral Dilemmas. The Philosophical Review 1962;71(2):139–158.
28. Roe v, Wade. United States Reports. Vol. Vol 410. United States Supreme Court; 1973. p. 113
29. Cohen, J. Regulating Intimacy: A New Legal Paradigm. Princeton: Princeton University Press; 2002.
30. Convention for the Protection of Human Rights and Fundamental Freedoms. Vol ETS 5.
31. Levine, RJ. Ethics and Regulation of Clinical Research. Vol. Second Edition. New Haven: Yale University Press; 1988.
32. Jenkins VA, Fallowfield LJ, Souhami A, Sawtell M. How do doctors explain randomised clinical trials to their patients? Eur J Cancer 1999;35(8):1187–1193. [PubMed: 10615228]
33. Swanson GM, Ward AJ. Recruiting Minorities Into Clinical Trials: Toward a Participant-Friently System. J Natl Cancer Inst 1995;87(23):1747–1759. [PubMed: 7473831]
34. Benson AB, Pregler JP, Bean JA, Rodemaker AW, Eshler B, Anderson K. Oncologists' reluctance to accrue patients onto clinical trials: an Illinois Cancer Center study. J Clin Oncol 1991;9(11):2067–2075. [PubMed: 1941065]
35. Glickman SW, McHutchison JG, Peterson ED, et al. Ethical and Scientific Implications of the Globalization of Clinical Research. N Engl J Med 2009;360(8):816–823. [PubMed: 19228627]
36. Brassington I. John Harris' argument for duty to research. Bioethics 2007;21(3):160–168. [PubMed: 17845487]
37. Allhoff F. Free-riding and research ethics. Am J Bioeth 2005;5(1):50–51. [PubMed: 16036662]
38. Chan S, Harris J. Free riders and pious sons: why science research remains obligatory. Bioethics 2008;21(3):1–11.
39. Stern JM, Simes RJ. Publication bias: evidence of delayed publication in a cohort study of clinical research projects. Br Med J 1997;315:640–645. [PubMed: 9310565]
40. Barnes K. Pharma giants risk reputation through clinical trial cost-cutting. Outsourcing-pharma.com. 2006
41. 101 Facts about Clinical Research 10/6/08. [Accessed 3/30/09]. http://www.ciscrp.org/information/documents/101FactsaboutClinicalResearch.pdf
42. Sung NS, Crowley WF, Genel M, et al. Central challenges facing the national clinical research enterprise. JAMA 2003;289(10):1278–1287. [PubMed: 12633190]
43. Sharp RR, Yarborough M. Additional thoughts on rethinking research ethics. Am J Bioeth 2005;5(1):40–42. [PubMed: 16036657]
44. de Melo-Martin I. A duty to participate in research: Does social context matter? Am J Bioeth 2008;8(10):28–36. [PubMed: 19003704]
45. Kenny C. Why are we worried about income? Nearly everythign that matters is converging. World Development 2005;33(1):1–19.
46. Beecher H. Ethics and Clinical Research. N Engl J Med 1966;274:1354–1360. [PubMed: 5327352]