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VIEWING RESEARCH PARTICIPATION AS A MORAL OBLIGATION:

In Whose Interests?

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Abstract

A moral paradigm shift has proposed for participation in health-related research. It's not just a praiseworthy option, some say; it's a social obligation. Recasting research participation in this way would have global ramifications, however. Who ultimately stands to gain the most from it, and who has the most to lose?

Over the past few years, a growing number of people have called for reconceptualizing participation in health research as a moral obligation. John Harris argues that seriously debilitating diseases give rise to important needs, and since medical research is necessary to relieve those needs in many circumstances, people are morally obligated to act as research subjects.[1] Rosamond Rhodes claims that research participation is a moral obligation for reasons of justice, beneficence, and self-development: because we all benefit significantly from modern medicine, we are all required to do our part in advancing the state of medical knowledge.[2] Individuals who reap the benefits of medical knowledge without contributing through research participation are not only acting unfairly toward others, but acting against their own self-interest. G. Owen Schaefer and colleagues argue that "because the enterprise of biomedical research produces the important benefit of medical knowledge that is an advantage to all, every individual has an obligation to support that system of knowledge generation by participating in biomedical research."[3] For this reason, they write, individuals normally ought to participate in clinical trials when presented with the option.

At the same time, such claims come with some important qualifications. Like most obligations, the moral obligation to participate in research is prima facie or not absolute; it may be legitimately overridden in particular cases by other important concerns. Moreover, there is no moral obligation to participate in research when, for example, the potential risks to the individual far outweigh the expected benefits, when a study is poorly designed, or when the research has not been reviewed by a (competent) ethics committee. However, for those who advocate this view, the crux is that there *is* a moral obligation to participate in biomedical research. For once the moral obligation exists, the burden of proof shifts: instead of individuals needing good reasons to sign up for research studies, they should participate in research unless they have good reasons not to.

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Conceiving research participation as morally obligatory conflicts with the commonly held view that agreeing to join a research study is morally praiseworthy, recommended, or supererogatory. The idea that research participation is valuable but not obligatory is expressed (implicitly or explicitly) in many influential research ethics guidelines and regulations, embodied in current research practices, and defended in influential discussions about the ethics of research involving human subjects. Recasting research participation as obligatory is therefore not a minor philosophical quibble about the moral status of an action. Viewing research participation in this way would constitute an ethical paradigm shift with global ramifications, analogous to other efforts to promote particular religious or secular moral views around the world.

Some preliminaries are in order. By research *participation*, I mean individuals agreeing to be research subjects and following relevant protocol procedures. One could broadly understand "participation" as contributing to the practice of research in general, including tax contributions. However, ways of contributing to research other than volunteering to be a research subject are not the focus of this paper because the heart of the ethical discussion is about the more controversial issue of individual research participation, not about general research support. By *moral obligation*, I mean the following: if an action is morally obligatory for a person, then that person is the appropriate object of negative moral attitudes (such as blame) if he or she fails to perform that action, unless he or she has a legitimate excuse. This definition of (prima facie) moral obligation is fairly standard and distinct from acts that are morally permissible. There is no blame-worthiness attached to the failure to perform morally permissible actions, though other disapproving attitudes may be warranted. By *health-related research*, I mean research that is performed on human subjects and in which the ultimate goal is to improve the health of individuals and populations. I use the term this way, rather than to refer to any research involving human subjects, because it illustrates the strongest case for research being obligatory. I describe the research as "health-related" (rather than as "biomedical") to avoid the impression that the debate is exclusively about participation in clinical trials. Other kinds of health research can also contribute to significant health improvements. This paper focuses on participation in health-related research as a moral obligation in the above-defined terms.

I also want to distinguish two ways of conceiving research participation as a moral obligation. According to a *general* conception, participation in health-related research is prima facie morally obligatory. Individuals have a standing moral obligation to participate in health-related research unless they have strong reasons not to do so. According to a *particular* conception, some health-related research is morally obligatory, but some is not. According to the latter view, the moral status of research participation is not uniform; instead, it is determined on a case-by-case basis, depending on variables such as the condition studied, the type of research, or special features of prospective participants. This paper largely focuses on the general conception, as this is the central focus of the current debate, though I will suggest the particular conception may ultimately be more defensible.

Arguing for Research Participation as Moral Obligation

Surveying the existing literature, there are three key arguments in favor of the general claim: the rescue argument, the free-rider argument, and the public good argument.[4] I will briefly describe the core claims of these arguments and their strengths before analyzing some shared underlying weaknesses.

According to the rescue argument, our obligation to participate in health-related research follows from a more basic obligation to prevent harm to persons. Health-related research has developed products (for instance, antibiotics and surgical advances) that have prevented or treated serious harms. Many people would be much worse off if health-related research had not taken place in the past. People who fail to participate in health-related research fail to prevent these harms, and if they have no legitimate excuse for not participating, then they are blameworthy.

According to the free-rider argument, if we have benefited from health-related research in which others have participated as subjects, then we have a moral obligation to do likewise. A glance at our medicine cabinets reveals that we all benefit from health-related research, in one way or another, and human subjects' past participation in research has helped make these benefits possible. Individuals who enjoy the fruits of research without bearing the burdens of research participation are therefore blameworthy. Here, blameworthiness consists in unfairness rather than failure to prevent harm.

According to the public good argument, individuals have a moral obligation to participate in health-related research because the knowledge and products developed through this research are public goods—a valuable resource of advantages and benefits that can be shared among present and future generations. Analogies are often employed in support of the argument. For example, clean air and democratic institutions are public goods, and therefore, people have a moral obligation not to drive cars that produce a lot of pollution and to participate in the democratic process by voting. According to this view, those who fail to contribute to public goods without a valid excuse are blameworthy. What makes failure to participate in research blameworthy here is neither harm nor justice, but civic responsibility and broad self-interest. Citizens ought to care about the benefits of health-related research for present and future generations, just as they should care about other public goods.

These three arguments can be put forward simultaneously. One could claim that those who do not participate in health-related research are indifferent to the suffering of future persons, unjustly benefit from sacrifices made by past research participants, and neglect responsibilities to the society that their descendents will inherit and from which they have gained significant advantages. The power and attraction of the arguments—either singularly in combination—derive from the important moral values they appeal to: prevention of harm, justice, and social responsibility.

Unresolved Issues

However, these arguments are diluted by a number of unresolved issues that those who believe research participation is an obligation have not adequately addressed. One

unresolved issue is philosophical: when are reasons in favor of an action strong enough to make that action morally obligatory? Typically, there are some moral (and practical) reasons to act and some moral (and practical) reasons not to act, or that favor a different action. Moral reasons in favor of an action are necessary, but not sufficient, to make that action morally obligatory. What is required for an action to be judged morally obligatory, rather than merely morally praiseworthy or worth encouraging from a moral point of view? One might intuitively think that the reasons in favor of the action must be especially strong or compelling. But even strong moral reasons in favor of an action do not necessarily make it obligatory.

For example, one may have very good reasons to volunteer to help homeless people after work rather than going to the gym, and while doing the former may be worth encouraging, it is not obvious that choosing the latter is necessarily blameworthy.[5] So what extra is needed? On some accounts, for an action to be morally obligatory, there must not only be good moral reasons in favor of that action, but existing social expectations supporting those reasons and giving them force. As Susan Wolf argues, we may have good moral reasons to volunteer at a rape crisis center (rather than go to the gym), avoid eating all animal products, or scrupulously avoid using the male pronoun to refer inclusively to men and women, but there are not (or not yet) sufficiently strong social expectations to unambiguously justify attributions of moral obligation and blameworthiness in such cases.[6] Research participation may not currently have the network of social expectations necessary to give it the force and authority of a moral obligation, despite whatever virtues the rescue, free-rider, and public goods arguments may have.[7] What makes an action obligatory—and failing to perform it blameworthy—is a matter of continuing philosophical debate. My point here is that proponents of the view that research participation is obligatory have generally assumed, without argument, that the reasons they offer are sufficient to constitute a moral obligation.

A common objection to the rescue, free-rider, and public goods arguments concerns alternative contributions to biomedical research. Let us assume that research participation *is* a moral obligation. It is possible to avoid being a free rider, to help prevent future harm to patients, and to contribute to the public good of health—to fulfill one's obligations, in other words—without personally becoming a research subject. One could, for instance, donate to a research wing of a medical hospital, offer a scholarship for young health researchers, or contribute to health-related research by paying taxes. And, of course, one is usually not a "free rider" in a literal sense because one pays for the benefits of health-related research, either directly or through insurance premiums.[8] Proponents of the general conception must demonstrate that, to obtain the goods connected to health-related research, research participation is required in addition to these other possible contributions.

But that is not all. If there were enough (or a surplus) of research participants, the case for research participation as a moral obligation would be as weak as moral appeals for blood transfusion volunteers when there is (and will be) no blood shortage. So the argument that research participation is obligatory partly rests on a utilitarian assumption: if more people volunteered for research, there would be more discoveries, leading to greater social benefits. Health-related research ought to be expanded as far as possible to maximize potential benefits, in which case there will never be enough research participants. Proponents of the

general conception rarely argue explicitly in support of this “maximizing” utilitarian assumption, nor do they dwell on its implications.

The validity of the above assumption partly depends on empirical facts about how health-related research is actually conducted and implemented. The arguments that research participation is a moral obligation—particularly the public good argument—are compelling to the extent that health-related research does in reality what it ideally is supposed to be doing: target important health needs and priorities and facilitate the implementation of successful research interventions into clinical and public health practice, thereby contributing significantly to improved population health.

All too often, however, reality sharply diverges from the ideal. For example, some health-related research— and particularly some pharmaceutical research—is not geared toward reducing significant morbidity and mortality in vast numbers, and its choices of research questions and investments may serve corporate interests rather than (or at the expense of) public interests. Research priorities do not match up with global health needs: the vast majority of the world’s health research expenditures are focused on diseases and conditions that affect only a small minority of its population.[9] When health research studies are increasingly devoted to the development of “me-too” drugs or treatments for minor (but marketable) ailments, we may begin to doubt the goal of maximizing health research in general and have suspicions about calls for ever more research participants. Such suspicions can be deepened by studies showing that industry-funded research tends to produce outcomes favorable to the research sponsor[10] or by cases where the results of unfavorable studies are concealed from doctors and patients.[11]

Another way of questioning the idea of research participation as a moral obligation involves the issue of health care access. In the United States, millions of uninsured or underinsured patients have no or limited access to many of the fruits of biomedical research. In developing countries, millions continue to suffer from diseases and conditions for which effective treatments or preventive methods were discovered by researchers decades ago. Do people have an obligation to participate in health-related research when there are serious gaps between the research and public access to successful health interventions? One could argue (following Rosamond Rhodes) that the injustice of limited health care access is irrelevant to the question of whether health research participation is obligatory; one should work to increase health care access while continuing vigorously to promote participation in health-related research, including research among marginalized populations. [12] But questions of access and obligation are not unrelated. Arguments that research participation is obligatory are premised on successful research products being accessible public goods, and to the extent that this is not the case, the argument is weakened.

Alternatively, one could (following Schaefer and colleagues) stipulate that there is no prima facie duty for an individual to participate in research if inequities preclude that individual from receiving the benefits of research.[13] But restricted access to research benefits should be a concern for everyone and should impact the moral status of research participation generally. Why should it be obligatory for me to participate in research only if I personally stand to gain from it, while many others will not have access to the potential benefits?

Again, the argument for moral obligation rests on the assumption that biomedical research is likely to produce publicly accessible health benefits, not just benefits to the participant, and chronic problems with health care access erode this assumption. To state the point more broadly: for participation to be obligatory, the research has to be important. It is unreasonable to blame people for not joining studies whose value is minor, ambiguous, or dubious.

Establishing criteria for determining the "importance" of health-related research is no easy task: should we understand it in terms of health indicators and outcomes or in terms of other measures, and if so, which ones? Those who see research as a moral obligation tend to sidestep the question of importance, relying largely on an intuition that biomedical research is important as a whole and selectively using famous examples of successful research (such as development of the polio vaccine and antibiotics) to support this intuition. Sociological data on what kinds of research are actually conducted and the political economy of how research priorities are made and how studies get funded not only reveals a mixed, less heroic picture, but also weakens the case that research participation is a moral obligation.

There is another, related question about the importance of health-related research. However this importance is understood, it is bound to take into account avoidable morbidity and mortality. But morbidity and mortality can be (and often are) positively affected by factors other than healthrelated research. The incidence of tuberculosis fell sharply due to improvements in housing conditions and hygiene *before* the discovery of the tubercle bacillus in 1882 and the discovery of Streptomycin in 1943. On a social determinants of health model, health-related research is just one determinant of good health among many.[14] Health is often more effectively improved by attending to known causes of poor health—like poverty—than by conducting or joining health research studies, whose future impact on health is uncertain.[15] Showing the relative importance of health-related research—either by comparing it to other ways of improving health or by exposing the less reputable aspects of contemporary health research—dilutes the case for regarding research participation as a moral obligation.

Global Implications

What might change, in practical terms, if research participation came to be regarded as morally obligatory? If the practical consequences were quite negative, these would constitute additional reasons not to change the current moral status of research participation. Those who defend such a change need to demonstrate that such negative consequences are unlikely, or that there are counterbalancing positive consequences that allow the overall benefits to outweigh the costs. They must also take into account the impact this change is likely to have among vulnerable populations in low-income countries whose only access to adequate health care may come from participating in research, since these countries are increasingly where health-related research takes place.[16] Three potential areas of concern, if research is considered morally obligatory, are informed consent, participant recruitment, and the ethical review of research.

Informed consent

If health-related research is morally obligatory, is participation a genuine choice? Does it still make sense to ask for consent when research is a duty? In principle, obligation is compatible with choice. If I have a moral obligation to repay a debt, I can still choose not to repay and face the consequences. Similarly, if I have a moral obligation to participate in research, I can choose to decline. In both cases, however, my freedom is restricted in the sense that blame attaches to a failure to do the obligatory. If someone expresses reluctance to join a study, researchers would be justified in using powers of persuasion—short of coercion—to gain agreement. One downside is that people may chose to enter studies to avoid being regarded as blameworthy by health authorities, rather than basing agreement on their understanding of study benefits and risks.

Recruitment and retention

Schaefer and colleagues approvingly state that calling research participation morally obligatory would change how studies are advertised and potential participants recruited. Research advertisements could be similar to voting initiatives, morally exhorting the public to "do its part," and researchers could be allowed to recruit more aggressively, since they would, in effect, be helping people to do their duty.[17] Would it still be appropriate (as is now commonly part of the consent process) to tell participants that they can leave a study at any time, for any reason, and without penalty? Schaefer et al. do not say, but it is inconsistent to frame research participation as a moral obligation on the one hand, and on the other hand, to tell participants they are simply free to leave a study. It would be more consistent to use persuasion—again, short of coercion—to keep participants in a study. One way of doing this would be to label departure from a study as being unethical or wrong.[18] In a similar spirit, some contract research organizations and other for-profit research organizations currently employ "hard refusal" recruitment techniques. This involves repeatedly contacting prospective participants by phone, email, and correspondence until the person unambiguously states that he or she does not want to participate. Such proactive recruitment practices—borrowed from marketing research—acquire a moral justification if research participation is framed as an obligation and could become the rule rather than the exception.

Role of ethics review

How might the ethics review of research change if research participation was understood as a moral obligation? According to some, as long as review boards function well and ensure that individuals do not participate in excessively burdensome studies (in other words, those where burdens outweigh benefits), then research participants are adequately protected.[19] However, we have some reason to believe that ethics committees would indeed review studies differently, grounded in the notion of "benefit" and the dynamics of the weighing of benefits and risks. When research participation is seen as morally obligatory, the focus of attention would be drawn more to the *social* benefits of research than to benefits for individual participants. Ethics committees would likely concern themselves to a greater extent with the likelihood and magnitude of the health-related public good that a study might produce.

This is not to say that burdens and risks to participants would not enter into consideration, or that highly risky studies would be considered acceptable as long as the social benefits were sufficiently great. What it could entail is an overall higher tolerance for risk to research subjects, now that social benefits are being weighed against risks to individuals who are morally obligated to participate. Or, to put it another way: if health-related research is so important that participation becomes a moral obligation, why *shouldn't* participants be subjected to more risks? We permit other people—like soldiers, policemen, and firefighters—to face heightened risks when fulfilling their crucial social duties and protecting other public goods. It seems to follow that ethics committees would be less risk-averse in their reviews under this new dispensation, for the same reasons that they would allow for more aggressive recruitment and retention methods and permit researchers to engage robustly in moral persuasion.

Viewing research participation as morally obligatory would clearly provide researchers with powerful new tools: they could appeal to a prospective participant's sense of duty (or guilt) and employ a wide range of persuasive means to draw people into research studies. Calling research participation obligatory would also help researchers retain subjects by shifting the burden of providing justification onto participants who no longer wish to continue. Ethics committees would facilitate the process of increasing the numbers of research participants by approving studies with a higher level of risk than they might otherwise accept.

One nagging question, however, is whether making research participation obligatory goes hand in hand with the disempowerment of research participants, particularly the poor, illiterate, and marginalized. How can one say that a street vendor in India, a sheet metal worker in Poland, or a housewife in rural Uganda has a moral obligation to participate in (largely externally funded and led) health-related research, particularly if their community may not enjoy the social benefits of the research? Research increasingly takes place across vast inequalities among funding agencies, researchers, research institutions and companies, host countries, participants, and communities. One might argue that a moral obligation exists in such cases if participants and communities will gain benefits down the road[20] or if during the research, there is a fair exchange of some valued benefits among researchers, participants, and communities.[21] But with the inequalities that currently affect the world, the lion's share of research benefits (in terms of researcher prestige and livelihood, capacity-building, patents, drug development, health improvements, or profits) tend to flow to those already better-off, and health-related benefits from research may not be integrated into developing countries' local health systems even decades later.[22] Given this, in addition to other possible practical implications noted above, do we really want to call research participation morally obligatory?

Let us consider two possible counterarguments. First, imagine the following scenario. A research study in Uganda is directed at a health condition that afflicts many Ugandans. In addition to benefits that study participants will receive (such as free diagnostics and other ancillary health care benefits), the study funders have agreed to provide benefits to the local community in the form of, say, building a new health clinic. In this case, would it be inappropriate to claim that participation of individual community members (who pass the inclusion criteria) is morally obligatory, and that if they do not join, they would be doing

something morally wrong? There are a number of complex issues at play here. One could possibly make a case for moral obligation if one assumes several things—that the health condition studied trumps other important health priorities in the country, that this study in particular is very important in tackling that condition, and that the clinic will save a significant number of lives. However, this is not an argument for regarding participation in biomedical research in general as a moral obligation; it is a possible argument for a particular research study under certain conditions being a moral obligation. And even the more modest argument can still be considered controversial. What (if anything) does consent mean if individuals are morally obliged to participate in a research study because their impoverished community has been promised important side benefits?

Second, one could argue that viewing research participation as morally obligatory could have positive consequences from the standpoint of social justice. Currently, participants in health-related research tend to come disproportionately from socially underprivileged groups: those with poor health indicators and those for whom health-related research may be most attractive, such as poor populations at risk for infectious diseases and without access to basic health care. Making research morally obligatory for all social groups might alleviate the injustice of the socially disadvantaged groups bearing the greater burden of research participation by more equitably spreading the burden.[23] However, those with greater social, economic, and political power could evade such obligations with little cost to themselves. The situation is analogous to military service: to have proportional numbers of recruits from all social classes, something stronger than appeals to moral conscience would be necessary. A more equitable spreading of the burden would probably require research participation to be legally compulsory—like a policy of military conscription—and not just morally obligatory. (Research participants would then be analogous to citizen-soldiers engaged in a war against poor health.) Even those who strongly believe research participation should be regarded as morally obligatory tend to recoil from this extreme position.

Should the Paradigm Shift?

Given the issues raised in the foregoing sections, many questions require answers. Why should we change? What was so wrong about the traditional view that such a massive alteration is required? Is it just to increase the number of participants? Are we incapable of doing that by other means? Why is there this push to increase the number of research participants anyway? Are we supposed to believe that because health-related research has produced significant benefits in the past, we are morally committed to maximally increasing research participation ad infinitum?

To discredit the idea of research participation as obligatory, Hans Jonas famously tried to debunk the importance of health-related research as a whole. He provocatively claimed that society could survive and even flourish if no research on cancer and heart disease was conducted at all and people continued to die of these conditions at the current rate of incidence.[24] Those wary of regarding research participation as obligatory do not have to go this far. One can affirm that *some* health-related research is important—even *very* important—without implying a change in the overall moral status of research participation. One might even argue that, in specific studies with certain conditions, a solid case could be made that

certain participants are morally obligated to join. Alternatively, research participation could be regarded as an imperfect duty—in other words, a duty in suitable circumstances to give reasonable consideration to participating in research during the process of weighing different possible options for action.[25] (Having an imperfect duty to participate in research is compatible with blamelessly choosing to do something else.) Research participation would be one important imperfect duty among many that individuals have, along with imperfect duties to donate money to reputable charities, for example, or to use one's expertise to help the disadvantaged. These theoretical possibilities are worth further exploration, but the point here is the contrast with the more robust, general conception of research as a moral obligation: to defend the latter, you need a more inflated conception of the importance of health-related research than reality can bear.

The moral status of research participation cannot be separated from its history. Nazi experimentation and abuses, at least in part, consolidated the view that participation in research should not be obligatory in order to protect research participants from exploitation by more powerful stakeholders. Nor can the moral status of research participation be separated from possible underlying motivations. In whose interest is a change of status from nonobligatory to obligatory? Who ultimately stands to gain the most from it, and who has the most to lose? Health research has become a vast international industry, and changing the moral status of research participation serves the political and economic interests of its biggest players. It is probably no accident that calls to change the moral status of research participation come at a time when health research is increasingly being outsourced and off-shored around the world: relocating research in lower-income countries and framing research participation as a robust duty are mutually reinforcing ways of enhancing power and profitability. So at least in the short term, the chief beneficiaries of calling research participation "obligatory" are researchers, research institutions, public and private research funding agencies, and pharmaceutical companies. Those who believe that all of us, globally, will benefit—and benefit equitably—from this radical change have an unusually profound if not misguided faith in these institutions.

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