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Research Participation: Are We Subject to a Duty?

Robert Wachbroit, Institute for Philosophy and Public Policy, University of Maryland
David Wasserman, Institute for Philosophy and Public Policy, University of Maryland

Rhodes (2005) argues that contemporary research ethics has placed excessive emphasis on informed consent, overshadowing other ethical concerns about the conduct of biomedical research. We share her misgiving about the mechanical invocation of informed consent, the distorted understanding its theoretical underpinnings in the concept of autonomy (Wachbroit and Wasserman 1995), and the relative neglect of issues concerning the risks, benefits, and value of research. She then argues for the recognition of a duty to participate as research subjects in biomedical experiments, a duty that she claims has been obscured by a distorted understanding of autonomy. While we agree with many of her criticisms of prevailing views of autonomy, we believe that her case for a duty of research participation—never mind her proposal for a policy to implement it—is far from compelling. We will look at several arguments and conclude that none can support a duty as specific as she requires.

For Rhodes, our duty of research participation rests on a concern about free riding (Rhodes 2005). It starts with the plausible assumption that we all benefit to some extent from the enterprise of biomedical research. It then makes the uncontroversial claim that those who take part in research studies do so at some risk. It concludes that because

those who do not participate benefit from the risks incurred by those who do, the former are engaged in morally objectionable free-riding.

The second part of the conclusion does not follow from the first. An extra step is needed, to the effect that those who do not participate in research are *unfairly* benefiting from the efforts of those that do. Merely benefiting is not by itself morally objectionable. For example, we all benefit from the risks and burdens assumed by fire-fighters, but no one supposes that everyone thereby has a duty to be a fire-fighter. Indeed, every society of even modest complexity is built on a division of labor, under which individuals assume different burdens, as volunteers or as professionals, for mutual benefit. Some take on the burdens and risks of law enforcement, others take on the burdens and risks of fire-fighting, still others take on the burdens and risks of teaching. We all benefit by dividing the labor more than we would by serving as our own police, fire-fighters, and teachers. Of course there are disagreements over the proper division of labor, and there is always a risk that some will benefit without assuming any burdens, or adequate burdens. But under any division of labor, we will all benefit from some burdens we do not assume. Rhodes needs a further argument to show that our

obligations to those who participate in human experiments can only be paid in kind.

It is worth noting that Rhodes also needs to provide an *explanation* of what constitutes an in-kind obligation, since she believes that a duty to participate in research can be discharged in several ways—someone who receives the benefit of a particular kind of medical research need not be a subject in that research area. Thus, an individual who benefits from diabetes research is not thereby obligated to participate in diabetes research; she could participate instead in leukemia research, genetics research, etc. What is the principled basis for allowing only these sorts of trade-offs? If a diabetes patient can avoid the charge of free-riding by participating in leukemia research, why can't she also avoid that charge by tutoring in a Head Start program?

One might respond that progress in biomedical research can only be secured if a large and representative group of people participates as subjects. While we do not doubt that research would go at least marginally better with more, and more representative, subjects, we do not think that this is enough to establish an in-kind duty. The claim must be that biomedical research needs a more numerous or representative pool of subjects than it currently has access to.

Let us start with numbers. One might claim that more research participants are needed, so we all must pitch in. It's not clear how to assess the empirical claim on which this argument rests. It seems reasonable to conclude that if more research subjects were available, more research studies would be performed, but it doesn't follow that the extra research would be necessary or important. Our impression is that when researchers complain about needing more subjects, they typically need subjects with particular conditions or characteristics, not subjects in general. A universal duty of research participation would do little to meet their needs.

Next, consider representativeness. It could be argued that a universal duty of research participation serves weighty scientific interests. By relying on volunteers, we limit the generalizability of research findings. Perhaps there are slight but significant biological differences between people who volunteer and those who don't such that research on the former alone cannot claim general validity. For example, it might be that a drug that is shown effective in a clinical trial with volunteers might not be effective on people with the slightly different biology of non-volunteers. While such an empirical claim of biological difference cannot be dismissed out of hand, it should be clear that the burden of proof is on those who claim a significant difference. We are not aware of any current theories that would suggest a biological connection between, for example, disease susceptibilities and a willingness to participate in biomedical research.

But perhaps the relevant difference is not between volunteers and non-volunteers per se, but between racial, ethnic, or other groups with differential rates of volunteering.

For example, consider a subpopulation of people with biological conditions not shared by the wider population. Furthermore, suppose this subpopulation has suffered frequent abuse and injustices that have made its members wary of, if not hostile to, the institutions associated with biomedical research. It seems reasonable to expect that the members of this sub-population would not volunteer to participate, which might threaten the general validity of research conclusions. We may believe that members of such groups should set aside their suspicions and take part in research. But this is not because if they fail to do so, they will be free-riders, benefiting from the burdens assumed by the larger population. To the contrary, our concern is that their failure to participate will limit the applicability of findings to their group, perpetuating its exclusion from the benefits of health research. Claiming that they have a general duty of research participation does not really address this problem.

Finally, in drawing an analogy to jury service, Rhodes may be seen as claiming significant non-instrumental value in universal research participation. (Although some would deny that all members of the community should have a duty to serve on juries, let us assume they do for the sake of argument.) But the non-instrumental value of universal jury duty lies in a conception of procedural justice that gives litigants a right to have their disputes resolved by "a jury of their peers," and in a notion of equal citizenship that treats all adult citizens as peers for purposes of resolving such disputes. What non-instrumental value of research requires universal participation? Neither procedural justice nor equal citizenship appears to be tied to the recognition of a duty to serve as a research subject.

In conclusion, we believe that research participation should be seen as a valuable civic activity, like school tutoring, volunteer fire-fighting, and neighborhood patrolling. Like those other activities, it is a way for individuals to serve a community from which they derive many benefits. It should be encouraged and praised like those other activities, but there is no reason to single it out as the subject of a universal duty.

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