

Privatizing Biomedical Citizenship

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Genomic research is at an impasse. In the decade since the completion of the first draft of the human genome, few of the grand promised benefits of genomics have materialized. Biomedical researchers largely agree that one critical thing is essential to propel genomic promise and potential into the future and maintain its legitimacy: more bodies. In a prominent 2009 article, Ezekiel Emanuel, then Chief of the Department of Bioethics at the Clinical Center of the U.S. National Institutes of Health, and others from his office, made the case for promoting a social, if not formal legal, duty for all citizens to participate in biomedical research. This paper will examine this and similar calls to promote such participation as a new duty of modern citizenship in the context other federal initiatives directly seeking to enlist subjects into massive biomedical research enterprises and consider them all in relation to the recent reconfiguration of the National Institutes of Health to incorporate a new National Center for Advancing Translational Science (NCATS). The other federal initiative considered include 1) a multi-year study conducted by the Genetics and Public Policy Center at Johns Hopkins University for the NIH to study methods of effectively recruiting subjects to a national biobanks; and 2) the “Million Veteran Program”, an initiative of the Department of Veterans Affairs to enroll one million veterans in a massive biobanks to promote biomedical research; and 3) the passage of the Genetic Information Non-Discrimination Act (GINA).

This paper will argue that these efforts at massive recruitment are not simply motivated by a desire to drive biomedical research to its next stage of promised critical breakthroughs. They also critically involve a tacit promotion of a privatized notion of citizenship, whereby the duties of citizens are configured so as to serve, not the public good, but rather the good of private corporations – pharmaceutical manufacturers in particular. Here citizens are asked to participate to serve the public good of improving health, as they might serve on a jury or in the military. GINA serves as a critical adjunct to articulating this duty by reassuring prospective research subjects that data derived from their participation will not be used against them. What these arguments elide, however, is that where jury duty directly serves the polity, participation in research directly serves corporations seeking to develop new biomedical products and only indirectly promotes the public good. As recruitment efforts privatize citizenship to serve corporate interests, so does NCATS privatize the research resources of the federal government, essentially socializing the risk of drug discovery, to serve corporate interests – all in the name of serving the “public good” of health. There is a fundamental asymmetry in this model: citizens bear duties, government carries risk, and private corporations reap the commercial benefits without any concomitant duties or obligations. Indeed, by law corporations have only one duty – to maximize return to their investors.