PubPol 580 - Values, Ethics, and Public Policy, Fall 2009

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PubPol 580: Reading Notes for Class 15 (October 29, 2009)

On Thursday we’ll discuss biobanks, which house data collected from newborns. One website ([http://www.biobankcentral.org/importance/important.php](http://www.biobankcentral.org/importance/important.php)) says, “Biobanks are a critical resource for ... molecular-based biomedical research. The data, biospecimens – such as tissue or blood – and molecular components that they collect, test for quality, and then distribute to researchers are absolute requirements in the pathway to developing modern diagnostics and cures for human disease.”

Opponents of biobanks often argue that there is an individual right that trumps the social benefits argument. If such an argument is to be convincing the right (or rights) need to be clearly articulated, so as you do the reading think about how well opponents are doing that. Similarly, on the social benefits side of the argument, a clear articulation of what citizens stand to gain is a good starting point.

Then we can get down to resolving the problem—whether (1) we should acknowledge the right but override it because of the social benefits of doing so, (2) try to find a way to have our cake and eat it by finding a clever way to avoid the tension underlying the decision, (3) settle for a reduced level of social benefit that results from honoring some or all of the rights claims being advanced by opponents, or (4) concede the rights argument and forego the social benefits that might have flowed from the program.

To the presenters: I’d like one of you to make the argument for biobanks (option 1 or 2 above) and then the other can make the argument against biobanks (option 3 or 4). You can do these back to back, with no break for discussion in between. I have laid out the argument as one involving a choice between social benefits and rights. You may decide that some other way of framing the issue is more appropriate, which is OK. I’m mainly interested in hearing a strong pro-biobank argument and a strong anti-biobank argument as a way to start off the discussion.