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I agree in principle with the notion that whatever data is generated under federally funded research should be available to other researchers. But there is one, perhaps insurmountable problem: under current IRB regulations, an investigator must provide all IRBs overseeing a research project with the names and contact information of everyone who might access those data, even de-identified data. That is not possible under any data sharing agreement. And I don't know that I would agree with overriding individual IRB concerns and controls. If I were a subject in a research project, I would want to know who would be seeing and using my data.

Perhaps the solution would be having a 2-level consent statement (or 2-level waiver from the IRB): one giving the IRB-approved researchers access to the data, and one allowing the data to be shared broadly. A subject providing informed consent could decide whether anyone other than the investigators could see and analyze his or her data and could therefore restrict broad access without restricting local access by the study's investigators.

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