

GENETICS, PHILOSOPHY, SOFTWARE

A BROKEN CONTRACT

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Erika Check Hayden (who asked me by email before she wrote that piece) has a new article about "[A broken contract – as researchers find more uses for data, informed consent has become a source of confusion. Something has to change](#)". While I largely agree with her analysis of the current situation, her points for change are somewhat weakly described (BTW that paper already generated a heated discussion at The Mermaid's Tale: "[Informed consent — who's it supposed to protect, anyway?](#)").

The reported options "Vanderbilt synthetic derivative in which the data are scrambled with an opt out possibility", the "Brunner 3 option choice" or "Portable Legal Consent / Radical Honesty" do not really reflect the current discussion. Why is our earlier "[informed consent as process](#)" and the new PCI/patient centered initiatives so difficult to understand? At least the editorialist in the same issue "Time to open up" finds

As this journal has argued previously, a more appropriate solution to the conundrum of informed consent is to introduce greater openness to the process... Although some have argued that this approach, as well as patient-controlled approaches, will add time, cost and complication to studies, no one really knows if this is the case. Such concerns must not be allowed to derail the idea. Most large studies are funded by taxpayers or patient-advocacy groups. Researchers are therefore obliged to listen when patients and members of the public argue that they want to have more information — not less — to ensure that they agree to offer their continued participation in research.

Having been last week in Strasbourg for an EU consultation, I am tired of the German "broad consent" proponents repeating their old mantras. According to recent empirical research ("Europeans and Biotechnology in 2010 Winds of change?") 75% of all Germans asked in a survey, voted for "ask for permission before every new piece of research". That should be the norm, not the exception!

