

Blog

Research “Secrets” Revealed

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Chercheuse en résidence / Scholar in Residence

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It is with great pleasure, it seems, that this latest Quebec biomedical and genetic data bank, *Signature*, is being presented by those who established it and are now “[revealing its secrets](#).” One must wonder, though, about an apparently unrevealed secret: their way(s) of obtaining “informed consent” from

those having a psychiatric crisis which first makes them eligible for sample-taking and questionnaire completion.

Does a schizophrenic state undermine the ability to understand fully what the research comprises? Are those gathering the data independent of the researchers who will profit from it? Are there potential commercial opportunities for the use of the DNA data to be collected? These are only some of the issues that must be revealed.

If “advancing knowledge” is the rationale for doing things that may be problematic, *Signature* is clearly not the first or only research project to do so. But with the rapidly increasing privatization, commercialization, and yes, “precision medicalization,” of biomedical research, it becomes ever more urgent for this mantra to be questioned. Supposed “side effects” — as when drugs are tested — or “collateral damage” — as when family details are revealed through the study of even a “consenting” study participant — demand other perspectives insofar as these effects are actually built into the research process.

Bioethicists and all citizens need to discuss seriously what, if any, are the limits on research and practice. And since we have previously noted that the [exorbitant costs of attending meetings](#) mean too many voices cannot be heard in these hallowed halls, community-based conversations are urgent. Or is it already too late?

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