Fading

May 21, 2008 By Paul Dalton

I sit on Project Inform?s Institutional Review Board. IRB?s are one of the safety measures designed to ensure the safety and interests of research subjects are protected in the research process. PI?s IRB is meant to focus on community based research, particularly what is called ?investigator initiated? trials.

We hadn?t met for an entire year (OK, a year minus 3 days). Why? Nothing much to do. Even when we met last night, there was very little on our agenda.

There is just little of this kind of research going on. Some of the explanation is money- tighter competition for research dollars, more going to large research institutions and so on. Some of it is scientific ennui- a real lack of energy behind the kind of smaller scale, cutting edge research which typifies community based trials.

It is not just a shame, it is a problem. Most of the trials that are going on are coming from either industry or large institutions. There is nothing wrong with that kind of research- in fact some kinds of trials really should be coming from the companies or large networks. There is a conservative bent to this kind of research. It is not the best environment for cutting edge, creative kinds of research.

It makes me think, oddly of the Defense Department. They have a research group- called DAPRA (the Defense Advanced Research Agency), that does some weird, highly creative research- some of it downright wacky. The point is they have the freedom to do the kinds of research that has a high likelihood of failure, but also a big upside if it doesn?t.

My concern is a growing trend toward conservative, low risk, low reward, incrementalist research. I am all for incremental advances, but we need to try for the pie in the sky stuff as well. I am particularly interested in cure focused research. For a nice overview on the topic see https://www.poz.com/article/project-inform-leader-hiv-hepatitis-c-advocacy-likely-close

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